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PRINCIPAL INVESTIGATOR: Marvella Ford, Ph.D.

CONTRACTING ORGANIZATION: Henry Ford Health Sciences Center

Detroit, Michigan 48202

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Detroit, Michigan 48202			
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The study aims were to (1) use a randomized trial to evaluate an ongoing innovative intervention designed to facilitate screening adherence among African American men aged 55+ years in the screening arm of the Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial and (2) develop a survey to assess perceptions of cancer screening among African American men. No statistically significant differences were found in age, education or income between the intervention (n=301) and control (n=300) groups. A total of 9,949 calls have been made to intervention group participants to address competing needs preventing screening adherence. Survey items found through a literature search were placed into the Preventive Health Model framework. Two focus groups were held to evaluate the developing survey. Focus group results show cognitive/psychological factors of fear and anxiety regarding cancer diagnosis and lack of knowledge about screening tests and benefits. Wives and children were cited as the most important social support and influence persons affecting screening behavior. Programmatic/systemic screening-related factors included a trusted health care provider and health insurance. A final survey was developed. Abstracts were submitted for presentation at two national meetings. Study findings could help African American men benefit from participation in prostate cancer research.

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INTRODUCTION

SUBJECT AND PURPOSE OF THE RESEARCH

The objective of this feasibility study is to identify innovative methods for increasing the retention of African American men in prostate cancer screening trials. Retention, while important for all groups, is especially critical for African American men, given their often low representation in clinical trials. The specific aims are to evaluate the efficacy of a retention intervention in retaining African American men in the screening arm of the Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial at the Henry Ford Health System site, and to develop a culturally appropriate measurement instrument to assess perceptions of screening for these cancers among older African American men.

SCOPE OF THE RESEARCH

The study population consists of African American men aged 55 and older living in the Detroit area. Blocked randomization methods were used to assign the men to the retention intervention or control group. A retention coordinator provides intense follow-up to the men in the intervention group and will guide them through the PLCO Trial screening processes. Socioeconomic status is used as a covariate in later analyses.

It is hypothesized that men in the intervention group will show higher screening adherence rates than men in the control group. An instrument to assess cancer-screening perceptions among older African American men was developed using focus group techniques. The findings from this study will lay the foundation for randomized trials of the retention intervention (modified if necessary) in large prostate cancer screening or treatment trials involving African American men of different age groups. The psychometric properties of the measurement instrument could be tested for older and younger African American men. The instrument could then be used to help to identify potential study dropouts, who may need more intensive interventions in order to reduce attrition.

The retention study of African American men randomized to the intervention (screening) arm of the PLCO Trial began in June 1999 after five months of planning. In the retention study, 301 men have been randomly assigned to the intervention group and 300 men have been randomly assigned to the control group. The research protocol for the retention study has been approved by the Henry Ford Health System Institutional Review Board (HFHS IRB). An HFHS IRB continuation application was submitted and approved.

Retention study staff include Marvella E. Ford, Ph.D., Principal Investigator, Christine Cole Johnson, Ph.D., Co-Investigator, Michelle Jankowski, M.A.S., Statistician, Vernetta Randolph, Retention Coordinator, Danica Dixon-Macklin, Secretary, Toni Chociemski, Programmer and Mary Beavers, Data Manager. Consultants to the study include G. Marie Swanson, Ph.D. and Sally Vernon, Ph.D. On May 24, 1999 a Consultant Meeting was held with Drs. Swanson and Vernon. The meeting continued on May 25, 1999 with Dr. Vernon. The agenda for this meeting is included in Appendix A.

BODY

Statement of Work

African American Men in the PLCO Trial: Developing and Testing Methods to Increase Retention

Task 1. Develop and test the case manager/retention coordinator intervention in the PLCO Cancer Screening Trial

- (a) Hire and train the case manager/retention coordinator and train the other study staff (months 1-4)
- (b) Assign HFHS PLCO Cancer Screening Trial participants in the screening arm a socioeconomic status code and then assign them to the case manager/retention coordinator intervention group or to a control group (month 4)
- (c) Implement the retention intervention (months 5-28)
- (d) Conduct preliminary statistical analyses of the retention intervention (months 8-28)
- (e) Conduct final analyses (months 28-30)

Task 2. Develop a culturally appropriate measurement instrument to assess cancer screening perceptions of African American men

- (a) Conduct a literature search of existing instruments assessing cancer screening knowledge, attitudes, and beliefs among African American men (months 1-7)
- (b) Use the results of the literature search to document the reliability/validity, purpose and conceptual approach of each measurement instrument, and its cultural appropriateness for African American men (months 1-7)
- (c) Use the results of the literature search to develop focus group questions (months 8-12)
- (d) Hold a focus group session to assess participants' perceptions of the developing measurement instrument and to garner ideas for new questions (month 13)
- (e) Based on the focus group results, revise the measurement instrument (months 14-20)
- (f) Hold a focus group session to assess participants' perceptions of the revised measurement instrument (month 21)
- (g) Incorporate participants' suggestions into a further refinement of the instrument (months 22-30)
- (h) Conduct statistical analyses of the pilot study results (months 26-27)
- (i) Revise and refine the final measurement instrument, based on the pilot study results (months 28-30)

Progress related to each task in the Statement of Work is described in the following sections of the annual report.

Task 1 (a): Hire and train the case manager/retention coordinator and train the other study staff (months 1-4) A case manager/retention coordinator was hired and began training in month 1. However, she took another position at the end of month 2. A search was conducted for another case manager/retention coordinator, who was hired and trained in months 4-6.

Task 1 (b): Assign HFHS PLCO Cancer Screening Trial participants in the screening arm a socioeconomic status code and then assign them to the case manager/retention coordinator intervention group or to a control group (month 4)

Randomization (Figure 1) and other study procedures took place starting in month 6, once the case manager/retention coordinator was fully trained. Once individuals were identified as study participants, their home addresses were geocoded using census block group methods. Geographic information system (GIS) technology is an established computer mapping and analysis technology capable of linking geographic with demographic information.¹ Using GIS technology, Census was be used to assign each study participant the average household income in the block-group of residence (a subdivision of a census tract representing a city block).² This process has been found to be a valid and reliable method of assigning census-based characteristics such as socioeconomic status to study participants.²-⁴ Once geocoded, each case was assigned an income level code (low or moderate-to-high) based on Federal Register poverty guidelines and adjusted for household size. Low income level was defined as an annual household income < 1.5 times the poverty level, adjusted for household size.

Part of the retention coordinator's training consisted of contacting a large number of agencies serving community adults, particularly older adults, to develop a resource file of available community resources. These resources are shared with the study participants during the course of the study, as one of the study goals is to serve as an information clearinghouse for participants. In this manner, the case manager/retention coordinator addresses competing needs of the participants that may function to prevent them from adhering to their PLCO screening tests. The study procedures are documented in the following paragraphs. Study staff whose salaries appear on the retention study budget include: Marvella E. Ford, Ph.D., Principal Investigator; Vernetta Randolph, Retention Coordinator/Case Manager; Michelle Jankowski, M.A.S., Biostatistician; and Toni Chociemski, Programmer.

Retention Study Procedures

- 1) A data manager generated a list of all African American males in the PLCO Trial Intervention Arm (n=601).
 - This list only contained the names of active participants. It did not include people who were being tracked or lost to follow-up, deceased people, or people who have refused all further contact by PLCO staff.
- 2) The statistician on the retention study, Ms. Michelle Jankowski, randomized individuals on the list to Control or Intervention groups.
- 3) The Retention Coordinator, Ms. Vernetta Randolph, generated a list of study participants by Control and Intervention groups.
- 4) The group assignment information was forwarded to PLCO staff and a data manager generated separate Overview Sheets for each participant. The information on the Overview Sheets for each participant includes:

Demographic information
Study identification number
Screening examinations received (based on study year)
Telephone number(s) where participants can be reached

- 5) Before the retention study began:
 - a) Ms. Jankowski developed an Access database to record telephone calls and specific interventions for each participant.
 - b) Each participant's status (DOD-I or DOD-C) was inserted into the SMS scheduling notes.
- 6) The retention study participants were pulled from the PLCO Cancer Screening Trial database in July 1999, when the intervention was implemented.

These study procedures were further refined in the following manner.

- 1) Calls to the DOD-I and DOD-C study participants are made routinely (at least once per month for the DOD-I participants) by the Retention Coordinator (Ms. Randolph). The participants are called at approximately the same time of the month each month. That is, the participants scheduled to receive a call early in the month are called form the 1st through the 10th of each month. The participants scheduled to receive a call in the middle of the month are called form the 11th through the 20th of each month. Finally, the participants scheduled to receive a call during the latter part of the month are called from the 21st through the end of each month.
- 2) Approximately five days after the last scheduled call dates, Ms. Randolph, the Retention Coordinator, batches the call sheets and gives them to the data management staff. The schedule for this is as follows:
 - a) The call sheets for the first of the month calls are attached to a DOD cover sheet and are then given to the data management staff by Ms. Randolph by the 15th of each month.
 - b) The call sheets for the middle of the month calls are attached to a DOD cover sheet and are then given to the data management staff by Ms. Randolph by the 25th of each month.
 - c) The call sheets for the end of the month calls are attached to a DOD cover sheet and are then given to the data management staff by Ms. Randolph by the 5th of the following month.
- 3) The data management staff verify the number of call sheets given to them by Ms. Randolph. If there are any discrepancies the call sheets are returned to Ms. Randolph for correction.
- 4) Data management staff enter the calls into the study database and then return the call sheets to Ms. Randolph in approximately one week. Prior to returning the call sheets, the data manager verifies/documents, on the DOD cover sheet, the number of call sheets returned.

The DOD data cover sheet and the telephone call sheet are shown in the following pages.

DOD STUDY DATA COVER SHEET

DOD Study Retention Coordinator:		
DOD Study Data Manager:		

	Date	Number	Initials
Call Sheets Given to Data			() () () () () () () () () ()
Manager			
6			
Calls Entered into DOD Study			
database			
Call Sheets Returned to DOD			
Study Retention Coordinator			

"DOD Study: Retaining African American Men in the PLCO Cancer Screening Trial"

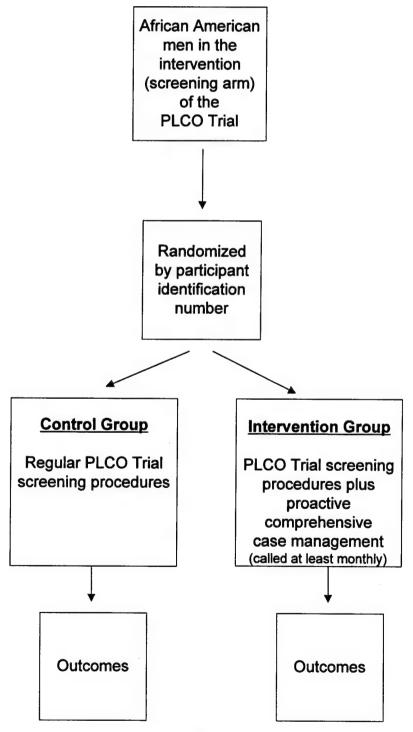
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NA AM CB Busy NPUB WN DISC	No answer Answering machine Asked to call back Busy Changed to non-published Wrong number Disconnected	1 2 3 4 5 6	Deceased Language barrier Refusal Unavailable Cannot trace Interview complete	2 Spo 3 Chi 4 Oth		1 2 3 4 5 6 7	Tuesday Wednesday

Final Outcome:____

Figure 1

African American Men in the PLCO Trial:
Developing and Testing Methods to
Increase Retention



Task 1 (c): Implement the retention intervention (months 5-28)

Due to the turnover in the case manager/retention coordinator position, the retention intervention began in July 1999. Retention intervention procedures related to scheduling are described in the paragraphs below. In addition, the investigators developed telephone scripts for each type of telephone contact, for use by the case manager/retention coordinator. These scripts are included in Appendix B. The Retention Coordinator (Ms. Randolph) was trained in the administering of these scripts during months 4-6. These scripts are tailored based on the following variables: each participant's study year; the types of exams each participant is scheduled to receive each year; and the extent to which each participant adhered to their scheduled screening exams in the previous year. Tailoring the scripts for each study participant allows barriers counseling specific to each individual to be conducted.

- A. Personal Identification (PID) numbers for each participant were printed on a listing generated by the PLCO data manager.
 - □ These PID numbers were used to generate an Annual Study Update (ASU) that is mailed to participants enrolled in the study.
 - □ Also from the PID listing, a participant overview form was generated. This form identifies which screening tests are needed.
- B. The PLCO data manager files the participant overview sheets and contact sheets by (a) study year, (b) randomization date, and (c) alphabetical order.
- C. The PLCO data manager gives Ms. Randolph the retention study participant overview sheets and contact sheets for the retention study participants with an upcoming annual screening examination. Retention study staff use a temporary filing system similar to that described in (B) to store documents on a temporary basis.
- D. Ms. Randolph checks the participant overview sheet to see which study year the person is in (e.g. T0, T1, and etc.) and she identifies whether the person is in the retention study intervention (DOD-I) or retention study control group (DOD-C).
- E. Ms. Randolph stamps the upper right corner of the participant overview sheet using a stamp inscribed DOD-I or DOD-C.
 - DOD-I: Intervention Group. For this group, Ms. Randolph places a call to each participants' home once a month to schedule screening appointments and address any human services needs. (At the start of the project, Ms. Randolph let the participant and his spouse/mate know that she would call the home monthly to talk with the participant.)
 - When establishing contact with the participant, Ms. Randolph asks to speak with the participant's spouse/mate and asks whether she/he has any human services needs. DOD-C: Control Group. For this group, Ms. Randolph only places a call to each participant's home to schedule screening appointments when needed.
 - Note: If a DOD-I participant had already received a scheduling call from PLCO at the beginning of the retention study, Ms. Randolph did not call the participant until the next month.
- F. For the DOD-C group participants, Ms. Randolph uses the standard PLCO scheduling script.
- G. For the DOD-I group participants, Ms. Randolph uses the enhanced scheduling script.
- H. Ms. Randolph schedules the appropriate screening appointment(s) using the PLCO scheduling method and stamps/writes DOD-I (Intervention) or DOD-C (Control) on the name line of the schedule form in the right corner.
- I. Ms. Randolph records all interactions with DOD-I participants in an Access database checklist. She enters text summarizing each discussion with each study participant in a Microsoft Word file. This information is updated daily.

- J. At the end of each business day, or prior to 7:30 a.m. of the next business day, Ms. Randolph gives the completed contact forms and overview sheets to the PLCO screening appointment schedulers.
- K. On Tuesdays, the PLCO screening appointment schedulers review all contact forms and overview sheets and once the information has been reviewed, the 'final' sheets are given to the PLCO secretaries, who prepare a typed schedule and add DOD-I and DOD-C to the name line, when appropriate. PLCO office staff instruct PLCO clinic staff to ignore the DOD-I/ DOD-C (across from participants' name) information that is added to the appointment schedule. The PLCO secretaries make a copy of the typed appointment schedule for Ms. Randolph. Ms. Randolph ignores all non-retention study participants when making her reminder calls for scheduled PLCO screening appointments, and therefore only calls retention study participants.
- L. The PLCO secretaries prepare 2 copies of screening appointment reminder letters and send one copy to the participant. Participants are instructed to call the general PLCO number to cancel or reschedule appointments. (See N) The other copy is placed in the participant's file along with the contact sheet and overview sheet. This information is filed in the PLCO scheduling office.
- M. The day before each retention study participant's scheduled screening appointment, Ms. Randolph places a reminder call to the retention study participant.
- N. If a retention study participant cancels his appointment during the reminder call, Ms. Randolph notes this information on her typed appointment list and notifies the PLCO screening appointment schedulers of the cancellation.
- O. Cancellations: The PLCO screening appointment schedulers contact the PLCO screening clinics regarding ALL cancelled appointments.
 - ☐ Ms. Randolph re-schedules all retention study participant appointments.
 - □ When a participant calls the general PLCO number to cancel a screening appointment, the PLCO screening appointment schedulers do not re-schedule the appointment, which is different than the PLCO process. Instead, the PLCO screening appointment schedulers notify Ms. Randolph, who then contacts the retention study participants to reschedule their annual screening appointments.

Originally, Ms. Randolph was only going to conduct scheduling calls for the participants assigned to the intervention group. However, one of the retention study's co-investigators pointed out the fact that a potential source of bias, "interviewer bias", would be reduced if Ms. Randolph, the Retention Coordinator, scheduled annual exams for participants in the intervention group and for participants in the control group. Therefore, scheduling procedures in the retention study were integrated with existing scheduling procedures in the PLCO Trial.

Retention Study Intervention:

In addition to scheduling annual screening appointments for the intervention group and control group retention study participants, Ms. Randolph proactively calls the DOD-I participants once a month. During each call, she ascertains participants' human services/ information needs (e.g., health insurance information, physician referral, health care condition-specific information, and local physicians who will see uninsured patients). Ms. Randolph leaves voice mail messages including her office telephone number for the DOD-I participants with whom she is unable to speak personally after repeated attempts to speak with them. When Ms. Randolph leaves these messages, she reiterates the fact that she is serving as a resource person for the participant.

Task 1 (d): Conduct preliminary statistical analyses of the retention intervention (months 8-28)

These findings were reported in the Annual Report.

Task 1 (e): Conduct final analyses.

Group comparisons between two categorical variables such as group and education were conducted using likelihood ratio chi-square tests. Group comparisons of mean age were tested using the Student's t-test. Tables 1-3 show that, as was the goal with the randomization process used in the present study, no statistically significant differences in educational level, age or income were found between the intervention group and the control group.

Table 1. Educational Characteristics of Intervention Group Members vs. Control Group Members

	Intervention Group*	Control Group	p-value**
·	(n=299)	(n=300)	
-	n (%)	n (%)	
Education			0.65
<8 years	17 (5.7)	14 (4.7)	
8-11 years	56 (18.7)	65 (21.7)	
12 years or completed high school	67 (22.4)	63 (21.0)	
Post high school training other than college	24 (8.0)	35 (11.7)	
Some college	79 (26.4)	71 (23.7)	
College graduate	22 (7.4)	24 (8.0)	
Postgraduate	34 (11.4)	28 (9.3)	

^{*}Some cases were missing data on the education variable

Table 2. Age Characteristics of Intervention Group Members vs. Control Group Members

	Intervention Group (n=301)	Control Group (n=300)	p-value*	
	n (s.d.)	n (s.d.)		
Mean Age (s.d.)	66.5 (6.3)	66.6 (6.0)	0.84	

^{*}Based on a student's t-test

^{**}Based on a chi-square test

Table 3. Income Characteristics of Intervention Group Members vs. Control Group Members

	Intervention Group*	Control Group*	p-value**
	(n=292)	(n=292)	
	n (%)	n (%)	
Income			0.79
Moderate-to-High	205 (70.2)	202 (69.2)	
Low	87 (29.8)	90 (30.8)	

^{*}Some cases were missing data on the income variable

Due to the randomized trial design of the retention intervention and the fact that the intervention will be continued in Phase II, results do not show the final outcome of PLCO Trial screening adherence based on retention intervention or control group status. This information will be analyzed at the conclusion of Phase II. Instead, Tables 4-10 show the results of analyses of the retention intervention by the study covariates of income, education and age.

Table 4 shows that among the intervention group participants, an inverse relationship was found between level of education (<8 years through post-college training) and income level (moderate-tohigh or low).

Table 4. Income Characteristics of Intervention Group Participants by Educational Level

	<8	8-11	12	Post-	Some	Coll.	⁺Coll.	p-value
	Years	Years	Years or	H.S.	Coll.	Grad^^	Grad ^{&}	
			H.S.*	(NoColl.)**				
	n (col %)	n (col %)	n (col %)	n (col %)	n (col %)	n (col %)	n (col %)	
Income								0.0013
Modto-High	19 (61.3)	70 (59.3)	87 (68.5)	39 (72.2)	100 (67.6)	37 (84.1)	53 (88.3)	
Low	12 (38.7)	48 (40.7)	40 (31.5)	15 (27.8)	48 (32.4)	7 (15.9)	7 (11.7)	
Total	31 (100)	118 (100)	127 (100)	54 (100)	148 (100)	44 (100)	60 (100)	

H.S.= High school diploma or equivalent

^{**}Based on a chi-square test

^{*}Post-H.S. (NoColl.) = Post-high school degree but no college degree

SomeColl. = Some college training but no college degree Coll.Grad = College graduate

[&]amp;+CollGrad = College degree plus at least some post-graduate training

Table 5 shows data related to the disposition of all calls made to the 301 intervention group participants through June 2001 (24th study month). It is important to note that the "Intro. Call" (Introductory Call) refers to the first call made to a participant during which some type of contact was made with the participant (either directly or via an answering machine, spouse, other family member, etc.), regardless of the actual month in which the call was made. The "1st Month Call" refers to calls made 30 days past the date of the "Intro. Call" (but less than 60 days past this date). The "2nd Month Call" refers to calls made 60 days past the date of the "Intro. Call" (but less than 90 days past this date); the "3rd Month Call" refers to calls made 90 days past the date of the "Intro. Call" (but less than 1200 days past this date), etc. Thus, many "Intro. Calls" occurred after July 1999, when the retention intervention began and Ms. Randolph, the Retention Coordinator, first began to make monthly calls to study participants. As may be seen in Table 5, each month, participants are contacted at a rate greater than once call per month per participant. Thus, Ms. Randolph often makes multiple calls to the study participants during each month. Table 5 also shows that the majority of study participants have not yet reached the time period of receiving their "24th Month Calls".

Table 5. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24th Study Month)

			Call Disposition	on		
	Answering	Spouse	Unknown	Participant	Other Family	Total
	Machine	Spouse	Person	1 articipant	Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Type of Call	=					
Intro. Call	182 (32.1)	32 (5.6)	111 (19.6)	233 (41.1)	9 (1.6)	567 (100)
1st Month Call	118 (25.1)	42 (8.9)	107 (22.7)	201 (42.7)	3 (0.6)	471 (100)
2 nd Month Call	118 (26.5)	27 (6.0)	81 (18.2)	215 (48.2)	5 (1.1)	446 (100)
3 rd Month Call	120 (29.7)	28 (6.9)	64 (15.8)	188 (46.4)	5 (1.2)	405 (100)
4 th Month Call	129 (31.9)	22 (5.4)	64 (15.8)	184 (45.4)	6 (1.5)	405 (100)
5 th Month Call	91 (25.2)	19 (5.3)	62 (17.2)	186 (51.5)	3 (0.8)	361 (100)
6 th Month Call	114 (27.2)	24 (5.7)	68 (16.2)	209 (49.9)	4 (1.0)	419 (100)
7 th Month Call	104 (26.1)	19 (4.8)	55 (13.8)	217 (54.5)	3 (0.8)	398 (100)
8 th Month Call	123 (28.6)	14 (3.3)	80 (18.6)	210 (48.8)	3 (0.7)	430 (100)
9 th Month Call	168 (31.4)	20 (3.7)	89 (16.7)	255 (47.8)	2 (0.4)	534 (100)
10 th Month Call	145 (32.9)	19 (4.3)	68 (15.4)	204 (46.3)	5 (1.1)	441 (100)
11 th Month Call	154 (31.6)	13 (2.7)	60 (12.3)	246 (50.5)	14 (2.9)	487 (100)
12 th Month Call	157 (34.0)	18 (3.9)	48 (10.4)	228 (49.3)	11 (2.4)	462 (100)
13th Month Call	181 (31.8)	26 (4.6)	45 (7.9)	295 (51.7)	23 (4.0)	570 (100)
14 th Month Call	118 (28.2)	25 (6.0)	36 (8.6)	229 (54.8)	10 (2.4)	418 (100)
15 th Month Call	86 (23.0)	20 (5.4)	29 (7.7)	221 (59.1)	18 (4.8)	374 (100)
16 th Month Call	93 (25.3)	14 (3.8)	19 (5.2)	236 (64.1)	6 (1.6)	368 (100)
17 th Month Call	78 (24.7)	11 (3.5)	17 (5.4)	194 (61.4)	16 (5.0)	316 (100)
18 th Month Call	99 (25.3)	19 (4.9)	35 (8.9)	224 (57.1)	15 (3.8)	392 (100)
19th Month Call	116 (28.2)	18 (4.4)	20 (4.8)	238 (57.8)	20 (4.8)	412 (100)
20 th Month Call	102 (26.7)	15 (3.9)	19 (5.0)	222 (58.1)	24 (6.3)	382 (100)
21st Month Call	68 (21.6)	17 (5.4)	4 (1.3)	216 (68.5)	10 (3.2)	315 (100)
22 nd Month Call	76 (24.7)	24 (7.8)	12 (3.9)	186 (60.4)	10 (3.2)	308 (100)
23 rd Month Call	88 (36.5)	15 (6.2)	6 (2.5)	118 (49.0)	14 (5.8)	241 (100)
24 th Month Call	12 (44.5)	3 (11.1)	0 (0)	11 (40.7)	1 (3.7)	27 (100)
Total Calls	2840 (28.5)	504 (5.1)	1199 (12.1)	5166 (51.9)	240 (2.4)	9949 (100)

Table 6 shows the disposition of all calls made to the 301 intervention group participants through June 2001 (24th Study Month) by month/year of call. As may be seen in this table, in the majority of cases, Ms. Randolph, the Retention Coordinator, is most likely to speak directly with the study participant. However, in cases in which the participant is not available, Ms. Randolph leaves messages with an answering machine. The scripts used when an answering machine is encountered or when the participant is not available are included in Appendix B. In each case, whenever a message is left, Ms. Randolph states her name, the name of the PLCO Cancer Screening Trial, and indicates that she is the participant's resource person. She also provides her telephone number at work and lets the participant know that he can call her at anytime if he or a family member, friend or neighbor would like information on any topic related to health or human services. Thus, whether a participant is contacted directly or receives a message from Ms. Randolph, the concept of having Ms. Randolph as a resource person is reinforced. Additionally, Ms. Randolph repeatedly attempts to speak directly with each participant each month, even if she has previously left a message for the participant during the same month.

Table 6. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24th Study Month) by Month/Year of Call

		(Call Disposition	on		
	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
12.0.000-2.000-1.00	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Type of Call						
07/1999	96 (30.0)	23 (7.2)	64 (20.0)	136 (42.5)	1 (0.3)	320 (100)
08/1999	142 (29.7)	33 (6.9)	101 (21.1)	199 (41.5)	4 (0.8)	479 (100)
09/1999	110 (28.1)	30 (7.7)	86 (22.0)	161 (41.2)	4 (1.0)	391 (100)
10/1999	115 (29.0)	23 (5.8)	69 (17.4)	186 (46.8)	4 (1.0)	397 (100)
11/1999	111 (27.7)	28 (7.0)	66 (16.5)	193 (48.1)	3 (0.7)	401 (100)
12/1999	130 (31.4)	21 (5.1)	57 (13.8)	202 (48.7)	4 (1.0)	414 (100)
01/2000	105 (25.4)	21 (5.1)	76 (18.4)	207 (50.1)	4 (1.0)	413 (100)
02/2000	102 (28.2)	21 (5.8)	51 (14.1)	187 (51.6)	1 (0.3)	362 (100)
03/2000	111 (24.9)	22 (4.9)	84 (18.8)	222 (49.8)	7 (1.6)	446 (100)
04/2000	149 (32.8)	17 (3.3)	78 (17.1)	211 (46.4)	2 (0.4)	455 (100)
05/2000	148 (30.0)	19 (3.9)	74 (15.0)	250 (50.7)	2 (0.4)	493 (100)
06/2000	167 (31.3)	21 (4.0)	78 (14.6)	253 (47.5)	14 (2.6)	533 (100)
07/2000	181 (34.9)	16 (3.1)	62 (11.9)	247 (47.6)	13 (2.5)	519 (100)
08/2000	166 (35.4)	22 (4.7)	31 (6.6)	231 (49.2)	19 (4.1)	469 (100)
09/2000	134 (29.4)	15 (3.3)	46 (10.1)	245 (53.9)	15 (3.3)	455 (100)
10/2000	99 (25.1)	31 (7.8)	32 (8.1)	222 (56.2)	11 (2.8)	395 (100)
11/2000	93 (24.1)	18 (4.7)	24 (6.2)	233 (60.3)	18 (4.7)	386 (100)
12/2000	57 (17.0)	12 (3.6)	17 (5.1)	243 (72.5)	6 (1.8)	335 (100)
01/2001	105 (25.2)	11 (2.6)	33 (7.9)	246 (59.0)	22 (5.3)	417 (100)
02/2001	118 (29.4)	21 (5.2)	19 (4.7)	228 (56.7)	16 (4.0)	402 (100)
03/2001	117 (29.2)	15 (3.8)	22 (5.5)	230 (57.5)	16 (4.0)	400 (100)
04/2001	60 (18.2)	18 (5.5)	11 (3.3)	217 (66.0)	23 (7.0)	329 (100)
05/2001	100 (28.7)	20 (5.7)	4 (1.2)	216 (62.1)	8 (2.3)	348 (100)
06/2001	124 (31.8)	28 (7.2)	14 (3.6)	201 (51.5)	23 (5.9)	390 (100)
Total Calls	2840 (28.5)	504 (5.1)	1199 (12.1)	5166 (51.9)	240 (2.4)	9949 (100)

Table 7 shows the disposition of all calls made to the 301 intervention group participants through June 2001 (24th Study Month) by age group. The data shown indicate that among participants aged <65 years, 44% of participants have been contacted directly by Ms. Randolph. In contrast, among participants aged 74+ years, 63% of participants have been contacted directly by Ms. Randolph. These findings suggest that the older participants may be less likely to be working and more likely to be retired and thus available to speak with Ms. Randolph, compared with the younger participants. Thus, the older participants appear to have a higher likelihood of being at home when Ms. Randolph calls each month. Ms. Randolph works until 8:00 p.m. one night per week as well as one Saturday per month, in an attempt to reach the participants who are difficult to reach during regular business hours.

Table 7. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24th Study Month) by Age Group

	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Age Group						
<65 years	1486 (32.6)	197 (4.3)	687 (15.1)	2007 (44.0)	184 (4.0)	4561 (100)
65-74 years	1078 (26.1)	232 (5.6)	399 (9.7)	2366 (57.3)	51 (1.3)	4126 (100)
>74 years	276 (21.9)	75 (5.9)	113 (9.0)	793 (62.8)	5 (0.4)	1262 (100)
Total	2840 (28.5)	504 (5.1)	1199 (12.1)	5166 (51.9)	240 (2.4)	9949 (100)

Table 8 provides confirmation that a statistically significant difference was found in the likelihood of speaking with the participant directly among younger vs. older participants. As may be seen, younger participants (aged <65 years) have been spoken with directly in 44% of all calls made by Ms. Randolph. In contrast, older participants (aged 74+ years) have been spoken with directly in 63% of all calls made by Ms. Randolph.

Table 8. Disposition of All Calls (Reaching the Participant vs. Contact with Another Source) by Participant Age Group

	Call Disposition				
	Participant	Other Contact	p-value		
	n (row %)	n (row %)			
Age Group			<0.001		
<65 years	2007 (44.0)	2554 (56.0)			
65-74 years	2366 (57.3)	1760 (42.7)			
>74 years	793 (62.8)	469 (37.2)			
Total	5166 (51.9)	4783 (48.1)			

Table 9 shows the disposition of all calls made to the 301 intervention group participants through June 2001 (24th Study Month) by participant income. The data in this table indicate that among individuals with moderate-to-high incomes, 51% of calls occurred in which Ms. Randolph spoke directly with the study participant. This percentage was similar (55%) among participants with low incomes.

Table 9. Disposition of All Calls Made to the 301 Intervention Group Participants through June 2001 (24th Study Month) by Participant Income

	Answering Machine	Spouse	Unknown Person	Participant	Other Family Member	Total
	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)	n (row %)
Income		W. B., A.				
Moderate-to-High	1995 (29.6)	329 (4.9)	827 (12.3)	3463 (51.4)	118 (1.8)	6732 (100)
Low	660 (23.3)	162 (5.7)	334 (11.8)	1560 (55.0)	119 (4.2)	2835 (100)
Total	2655 (27.8)	491 (5.1)	1161 (12.1)	5023 (52.5)	237 (2.5)	9567 (100)

Table 10 shows the disposition of all calls (reaching the participant vs. contact with another source) by participant income. Although the data shown in Table 10 are statistically significant, they are likely not socially meaningful, due to the similarity in row percentages of contact type by participant income.

Table 10. Disposition of All Calls (Reaching the Participant vs. Contact with Another Source) by Participant Income

	Participant	Other Contact	p-value
	n (row %)	n (row %)	
Income			<0.0013
Moderate-to-High	3463 (51.4)	3269 (48.6)	
Low	1560 (55.0)	1275 (45.0)	
Total	5023 (52.5)	4544 (47.5)	

Tasks 2 (a & b): (a) Conduct a literature search of existing instruments assessing cancer screening knowledge, attitudes, and beliefs among African American men (months 1-7) and (b) Use the results of the literature search to document the reliability/validity, purpose and conceptual approach of each measurement instrument, and its cultural appropriateness for African American men (months 1-7)

Three steps were involved in making progress toward developing a culturally appropriate measurement instrument to assess perceptions of cancer screening among African American men. First, a literature search on this topic was conducted. Potential instrument items that were apparent from this literature search are shown in the following section. The second step involved placing the identified items into a theoretical framework. In this step, the items were grouped into the explanatory framework of the Preventive Health Model. This model, which incorporates concepts from the Health Belief Model, the Theory of Reasoned Action, and the Social Cognitive Theory. In the third step, a smaller subset of actual focus group items were derived from the list of potential focus group items identified through the literature search.

Step One: Conducting a Literature Search to Identify Potential Survey Items

Focus group items that resulted from this literature search are listed in the following paragraphs of the report. The source of each set of items is identified.

SOURCE: Attitudes of African Americans Regarding Screening for Prostate Cancer. (Robinson and Haynes 1996) ⁹
ITEMS: What do you think would help to motivate Black men to get screened for cancer? What do you think are the most important reasons many African American men choose not to get screened for cancer? To what extent do you think that fear and mistrust of the medical establishment will keep Black men from getting screened for cancer? Do you think that some men fear the exam or test for cancer because it is associated with homosexuality?
SOURCE: Evaluating Focus Group Data: Barriers to Screening for Prostate Cancer Patients. (Dale 1998) ¹⁰
ITEMS: Does the fact that your doctor is a male/female affect your decision to get prostate cancer screening? Would embarrassment keep you from getting screened for prostate cancer? What kinds of things - good or bad - have you heard about the tests for prostate cancer? Would these things keep you from getting tested for prostate cancer?
SOURCE: Knowledge, Beliefs, and Prior Screening Behavior Among Blacks and Whites Reporting For Prostate Cancer Screening. (Demark-Whahnefried, Strigo, Catoe, Conway, Brunetti, Rimer, and Robertson 1995) ¹¹
ITEMS: Do you know someone who has had cancer? Is it possible to have cancer without having symptoms of this disease? What motivated you to get checked for cancer?
SOURCE: The Role of Focus Groups in Health Education for Cervical Cancer among Minority Women. (Dignan, Michielutte, Sharp, Bahnson, Young, and Beal 1990) ¹² ITEMS: Do you think that some people choose not to get screened for cancer because they cannot afford treatment if cancer were found? Do you have difficulty now in getting regular health care? What are some of the problems you are facing? (Ex: waiting time to get an appointment; waiting time at doctor's office)
SOURCE: Breast Cancer Screening: Racial/Ethnic Differences in Behaviors and Beliefs. (Friendman, Webb, Weinberg, Lane, Cooper, and Woodruff 1995) ¹³
ITEMS: What do you think is your risk of developing cancer, compared to other men of your age? Do you think that being older or being African American affects your chances of getting cancer? Does fear keep you from getting screened for cancer? What are some of your fears related to cancer screening?

Do you think that people don't get cancer screening because they just never get around
to it? Do you think that some people avoid getting screened for cancer because they are afraid
to think about cancer?
Do you agree that there is little hope for people with cancer?
Do you think cancer can be cured if it is found early enough?
SOURCE: Cancer Screening among African American Women: Their Use of Tests and Social Support. (Kang, Bloom, and Romano 1994) ¹⁴
ITEMS:
Do you think that:
Being married
Being a church member
Being a member of other types of organizations
Being encouraged by relatives and friends
would influence your decision to get cancer screening?
What could your spouse, church, other organization, relative or friend do to encourage your use of cancer screening tests?
Black-White Differences in Cancer Prevention Knowledge and Behavior. (Jepson, Kessler, Portnoy, and Gibbs 1991) ¹⁵
ITEMS:
Do you think that changing your diet can play a role in whether or not you get cancer?
Have you ever had a stool blood test?
Are you currently a cigarette smoker?
Do you exercise at least three times each week?
SOURCE: Factors Contributing to Health Promotion Behaviors among African-American Men. (Million-Underwood, Sanders 1990) ¹⁶
ITEMS:
Do you think that testing for cancer should be included as a part of your physical exam?
Do you think that doctors and other health care providers should talk to Black men about their
cancer risk?
Are you aware of the screening guidelines for cancer?
SOURCE: Behavioral Interventions to Increase Adherence in Colorectal Cancer Screening. (Myers, Ross, Wolf, Balshem, Jepson, and Millner 1991) ¹⁷
ITEMS:
If your doctor verbally recommended that you receive colorectal cancer screening, would this influence you to get the screening?
If you received a letter in the mail from your doctor, suggesting that you get colorectal cancer
screening, would this influence you to get the screening?
Which would have the greatest impact on your decision to get screened for colorectal cancer-doctor
recommendation (verbal), doctor recommendation (written), community leader recommendation-video or family member/friend recommendation?

Can you describe the kinds of tests that are done to check for colon – rectal cancer? (Ex: FOBT; Flex-sig)

What do you think are the benefits of colorectal cancer screening?

What are some of the drawbacks of this type of screening?

Would you get screened for colorectal cancer even if you hadn't been experiencing any symptoms of this disease?

What are some of the early warning sign of colorectal cancer?

What would be some of the barriers that would keep you from getting barrier that would keep you from getting screened for colorectal cancer? (Ex: cost, discomfort, time, not necessary)

SOURCE: Factors Associated with Intention to Undergo Annual Prostate Cancer Screening among African American Men in Philadelphia. (Myers ,Wolf, McKee, McGrory, Burgh, Nelson, and Nelson 1996)¹⁸

ITEMS:

Belief in the salience and coherence of screening

Belief in the efficacy of screening

Belief in the residual value of screening

Concern about screening-related physical discomfort and embarrassment

Screening-related influence of family members and friends

Do you think that the quality of your life would be better if you were tested for prostate cancer than if you were not tested?

Do you know what some of the possible health outcomes of prostate cancer treatment are?

Probe for: Incontinence

Impotence

Urethral Structure

Rectal Injury

Gynecomastion

SOURCE: Perceptions of Colorectal Cancer In a Socioeconomically Disadvantaged Population. (Price 1993)¹⁹

ITEMS:

Do you think homosexual men are more likely than other men to get colorectal cancer?

Do you think exercising regularly will affect your chances of getting colon cancer?

What about eating foods high in fat – does this affect risk of getting colon/rectal cancer?

Do you think that colon/rectal cancer runs in families? If so, what does this imply about cancer screening for members of these families?

Do you think poor, older, or Black people are more likely than other people to get colon cancer? Does having hemorrhoids increase risk of getting colon/rectal cancer?

Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

Which exams are used to detect colon/rectal cancer?

Are you embarrassed by the exams to detect colon/rectal cancer?

What would be some things that would keep you from getting checked for ____ cancer even if you wanted to get checked?

SOURCE: Prostate Cancer: Perceptions of African-American Males. (Price, Colvin, and Smith 1993)²⁰

ITEMS:
What are some of the early warning signs of prostate cancer?
Can prostate cancer be prevented?
Have you ever talked to your doctor about having your prostate examined?
Do you think that African American men are at higher risk than other men of developing prostate
cancer?
Does age have anything to do with likelihood of getting prostate cancer?
Are straight or gay men more likely to develop prostate cancer?
Compared to other men your age, do you think you are more or less likely to develop prostate cancer?
What are some of the benefits of prostate cancer screening?
What do you think are some of the barriers to prostate cancer screening among Black men? (Probe
for fear, shame, cost, time, uncomfortable exam, etc.)
SOURCE: African-American Males and Prostate Cancer: Assessing Knowledge Levels in the Community. (Smith, DeHaven, Grundig, and Wilson 1997) ²¹
ITEMS:
What is cancer?
Do you think people with cancer can live a normal life if they are treated for this disease?
SOURCE: Knowledge, Beliefs, Attitudes, and Cancer Screening Among Inner-City African-American Women. (Sung, Blumenthal, Coates, and Alema-Mensah 1997) ²²
ITEM: Are there people in your life with whom you discuss cancer?
SOURCE: Using Focus Group Methodology to Develop Breast Cancer Screening Programs That Recruit African American Women. (Williams, Abbott, and Taylor 1997) ²³ ITEMS:
Do you think that health care facilities are open at convenient times to allow cancer screening? Perception and Efficacy:
Do you think that the results of cancer screening are reliable?
Do you think that most people would have transportation to a health care facility if they decided to
get screened for cancer?
What are some ways you could learn more about cancer?
(Probe: Brochures, flyers and pamphlets from doctors' offices and in communities; radio ads;
billboards; newspapers; church bulletins; and magazine ads)
Do you think that screening advertising that featured well known African American men to
get screened for cancer?
What do you think messages designed to encourage Black men to get screened for cancer should say?
What do you think would be the best format for these messages? (Probe for print ads, TV, radio, magazines, etc.)
What role does spirituality play in the decision to get screened for cancer?

Task 2 (c): Use the results of the literature search to develop focus group questions (months 8-12) Step Two: Placing the Identified Potential Survey Items Into a Theoretical Framework

In the Preventive Health Model, four sets of factors are posited to be related to preventive intention and to carrying out this intention by actually engaging in preventive behavior. These factors are background factors, cognitive/psychological representation factors, social support and influence factors, and program factors. Background factors include sociodemographic characteristics, medical history, and past preventive behavior. Cognitive/psychological representation factors include perceived susceptibility to disease, worry about having the disease, interest in knowing diagnostic status, belief in disease prevention and curability, belief in salience and coherence of behavior, belief in efficacy of detection and treatment, belief in self-efficacy related to behavior, and concern about behavior-related discomfort. The social support and influence factor encompasses the support and influence of family members and health care professionals. Finally, program factors include provider actions that facilitate (or inhibit) preventive behavior.

The classification scheme of the Preventive Health Model, used to categorize each potential survey item identified through the literature search, is presented in the following section of the report.

Potential Survey Items that Are Background Factors:

Which of these groups best describe(s) you? (African American or Black, American Indian or Alaskan Native, Asian, Caucasian or White, Pacific Islander, or Other)

Is there another group with which you identify? If so, with which group? (African American or Black, American Indian or Alaskan Native, Asian, Caucasian or White, Pacific Islander, or Other)

Are you of Hispanic origin? (Yes or No)

What is your date of birth? Are you male or female?

Are you currently a cigarette smoker?

Do you exercise at least three times each week?

Potential Survey Items that Are Cognitive/Psychological Representation Factors:

Perceived susceptibility to disease - Is it possible to have cancer without having symptoms of this disease?

Are you aware of the screening guidelines for cancer?

Can you describe the kinds of tests that are done to check for cancer?

Would you get screened for cancer even if you had not been experiencing any symptoms of cancer?

What are some of the early warning signs of cancer?

What is cancer?

Do you know someone who had had cancer?

Do you think that poor people are more likely than other people to get cancer?

What do you think is your risk of developing cancer, compared to that of other men your age?

Do you think that being older affects your chances of getting cancer?

Do you think that cancer runs in families? If so, what does this imply about cancer screening for members of these families?

Do you think that African American people are more likely than other people to get cancer?

Worry about having the disease - What are some of your fears related to cancer screening?

Do you know what some of the possible side effects of cancer treatment are?

Interest in knowing diagnostic status - Do you think that some people avoid getting screened for cancer because they are afraid to think about cancer?

Belief in disease prevention and curability - What do you think are the most important reasons many African Americans choose not to get screened for cancer?

Do you think that the quality of your life would be better if you were tested for prostate cancer than it would be if you were not tested?

Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

Belief in salience and coherence of behavior - Do you think that some people do not get cancer screening because they just never get around to it?

Belief in efficacy of detection and treatment - Do you think that the results of cancer screening tests are accurate?

Do you think cancer can be cured if it is found early enough? If so, do you think that once they are cured, people can live a normal life?

What do you think are the benefits of cancer screening? Would these things motivate you to get tested for cancer?

What are some of the drawbacks of cancer screening? Would these things keep you from getting tested for cancer?

Belief in self-efficacy related to behavior - What would be some things that would keep you from getting checked for cancer even if you wanted to get checked?

Do you think that most people would have transportation to a health care facility if they decided to get screened for cancer?

Do you think exercising regularly will affect your chances of getting cancer?

What about eating foods high in fat - does this affect your chances of getting cancer?

Concern about behavior-related discomfort - Do you think that some men associate certain tests for cancer with being a homosexual (a man who prefers dating men)?

Would embarrassment keep you from getting screened for cancer?

Potential Survey Items that Are Social Support and Influence Factors:

Do you think that:

Being married

Being a church member

Being a neighbor

Being a member of other types of organizations

Being encouraged by relatives and friends

would influence your decision to get cancer screening? In what ways?

Which types of people or organizations would have the greatest influence over your decision to get screened for cancer?

Are there people in your life with whom you discuss cancer?

What do you think would help to motivate African American men to get screened for cancer?

What are some ways you could learn more about cancer?

Brochures/pamphlets

Flyers

Radio ads

Television ads

Newspaper ads

Church bulletins

Magazine ads

Billboards

Potential Survey Items that Are Program Factors:

To what extent do you think that fear and mistrust of the medical establishment keep Black men from getting screened for cancer?

Does the fact that your doctor is a male/female affect your decision to get cancer screening?

Do you think that some people choose not to get screened because they cannot afford treatment if cancer were found?

Has your doctor ever talked to you about having a cancer screening test?

If you have ever had a cancer screening test, did you talk to your doctor before you had the screening test? Did you talk to your doctor after you had the screening test?

What do you think messages designed to encourage African American men to get screened for cancer should say?

Do you have difficulty now in getting regular health care? If so, what are some of the problems you are facing?

Do you think that doctors and other health care providers should talk to African American men about their cancer risk? If so, what do you think these providers should say?

Do you think that testing for cancer should be included as a part of your regular physical exam?

Do you think that health care facilities are open at convenient times to allow cancer screenings?

Step Three: Developing a smaller subset of actual focus group items derived from the list of potential items identified through the literature search.

The focus group moderator's guide, including the final list of focus group items, is presented in the following section of the report.

Focus Group Questions for Cancer Screening Survey Development

> Facilitator: Marvella Ford Assistant: Deanna Hill Recorder: Felecia Collins

> Tuesday, January 25, 2000 6:00 p.m. - 8:00 p.m.

I. WARM-UP AND EXPLANATION (10 minutes)

A. Introduction

- 1. Good evening. My name is Marvella Ford. I work here at Henry Ford Health System. This is Deanna Hill. Deanna also works here at Henry Ford Health System. She will be assisting us this evening. Felecia Collins is the recorder this evening.
- 2. Thanks for coming.
- 3. Your presence and participation are important. Your thoughts and opinions that you discuss tonight are valuable in helping us to develop a survey about cancer screening.

B. Purpose

- 1. What we are doing here this evening is called a focus group. It's a discussion to find out your opinions.
- 2. We are interested in all of your ideas, comments and suggestions.
- 3. Each of you is very important and all of your comments are welcome.
- 4. There are no right or wrong answers.

Please speak up -- even if you disagree with someone else here. It's important that we hear what each of you thinks.

C. Procedure

- 1. We will be audiotaping and videotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later we'll go through all of your comments and use them to prepare a report on our discussion. However, all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected to your name. Also, if any questions make you uncomfortable, feel free not to answer them.
- 2. You don't have to wait for me to call on you. However, please speak one at a time, so the tape recorder can pick up everything.
- 3. We have many topics to discuss so I may change the subject or move ahead. Please stop me if you want to add anything.

D. Self-Introductions (Ice Breaker)

1. Please tell us your name and your dream vacation.

FOCUS GROUP QUESTIONS

1. What things come to mind when you hear the word "cancer"?

How do you feel when these things come to mind?

I typically use the words "African American" or "Black" but I was wondering which one you prefer to use? (USE THE WORD THEY PREFER. IF THEY DO NOT HAVE A PREFERENCE, USE "AFRICAN AMERICAN" AND "BLACK" INTERCHANGEABLY.)

- What do you think are some of the reasons some African American men choose not to get screened for cancer? Cancer screening means getting checked for cancer before you've ever had it.
- 3. Which types of people or organizations do you think have the greatest influence over the decision of Black men to get screened (or checked) for cancer?

Probe: spouse, neighbor, relatives, friends, church members, pastor, etc.

- 4. How much of a role do you think religion or spirituality play in the decision of Black men to get screened (or checked) for cancer?
- 5. What do you think are some of the benefits of cancer screening (or getting checked for cancer before you've ever had it)?

Do you think that these benefits motivate some Black men to get screened (or checked) for cancer?

6. What do you think are some of the drawbacks of cancer screening?

Do you think that these drawbacks keep some Black men from getting screened (or checked) for cancer?

- 7. What things do you think would motivate Black men to get screened (or checked) for cancer?
- 8. To what extent do you think that fear and mistrust of the medical system keep Black men from getting screened (or checked) for cancer?
- 9. Would the cost of cancer treatment if cancer is found keep you from getting screened (or checked) for cancer?
- 10. How much would embarrassment keep you from getting screened (or checked) for cancer?
- 11. What are some of your fears about cancer screening?
- 12. Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

What makes you say this?

13. Do you have difficulty now in getting regular health care?

If so, what are some of the problems you are facing (Probe: waiting time to get an appointment; transportation problems; cost; time away from work)

14. Do you think that testing for cancer should be included as part of the physical exam done by your doctor?

What makes you feel this way?

15. Do you think that doctors and other health care providers should talk to Black men about their cancer risk?

(If yes, probe: What kinds of things do you think doctors and other health care providers should say to Black men about their cancer risk?)

16. Does your doctor talk to you about your risk of getting cancer?

(If yes, probe: What kinds of things does your doctor talk to you about, in terms of your risk of getting cancer?)

17. What could your doctor do to encourage you to get screened (or checked) for cancer?

(Probe: verbal recommendations and/or letters suggesting screening)

18. Do you think that health care clinics and hospitals are open at convenient times for cancer screening (or getting checked for cancer before you've ever had it)?

(If not, probe: What could be done to make the times more convenient for people to get cancer screening?)

19. Do you think that using t.v., radio, newspaper and magazine ads to encourage Black men to get screened (or checked) for cancer would be effective?

(Probe for reasons why or why not: Let's start with t.v. ads...Now, let's talk about radio ads.)

(Probe: If men think ads would be effective say: What should these ads look or sound like? Who should be in them?)

- 20. How accurate do you think that the results of cancer screening tests are?
- 21. How likely do you think it would be for you to have cancer without having any signs or symptoms?
- 22. Do you know someone who has had cancer?
- 23. Do you think cancer can be cured if it is found early enough?

What makes you feel this way?

24. Do you think that people who have had cancer can live a normal life?

What makes you feel this way?

25. Do you think that your life would be better if you were screened (or checked) for cancer than it would be if you were not screened (or checked) for cancer?

(Probe: In what ways would your life be better? In what ways would your life not be better?)

- 26. Do you think that some men associate certain cancer screening tests with homosexuality or with men who prefer to date other men)?
- 27. How do you think that being older affects your chances of getting cancer?
- 28. How do you think that being African American affects your chances of getting cancer?
- 29. What do you think your risk is of getting cancer, compared to other men your age?

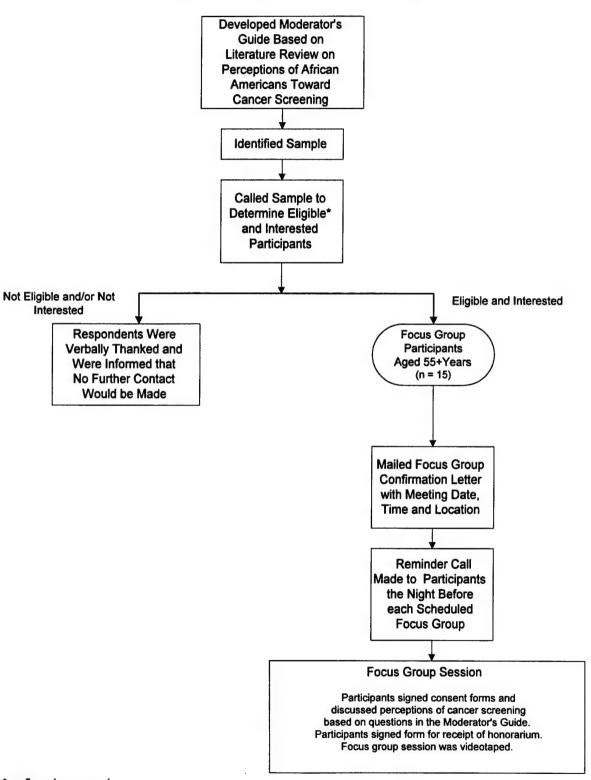
Thank you very much for coming today. Your comments are greatly appreciated. Everything that you have said tonight will help us to prepare a survey to look at perceptions of cancer screening.

Again, thank you very much.

Task 2 (d): Hold a focus group session to assess participants' perceptions of the developing measurement instrument and to garner ideas for new questions (month 13)

Figure 2

Methods Used in the Focus Group



*confirmed age, race/ ethnicity, and gender The study processes involved in identifying focus group participants are depicted in Figure 2. Basically, all African American men who had made at least one visit to Henry Ford Health System in the past year, and who were over the age of 55 years, were selected. Then, the names and birthdates of the men on this listing were compared with the names and birthdates of the African American men in the PLCO Trial. Men who were part of the PLCO Trial were excluded from participating in the focus group.

A random sample of the remaining names was taken, and given to trained telephone interviewers, who called the men on the list to invite them to participate in the focus group. During the telephone call, the interviewers confirmed the age and race of the men, and confirmed that they were not taking part in the PLCO Trial. If the men were not interested or able to participate in the focus group, they were verbally thanked for their time in taking the invitational telephone call. If the men were interested and able to come to the focus group, they were thanked. The interviewer continued calling the men until 15 men indicated that they would like to participate in the focus group. These men were then sent a reminder letter confirming the date, time, and location of the focus group. The night before the focus group was scheduled to take place, the 15 men received a reminder telephone call. At the conclusion of the focus group, the men signed a receipt and received \$25 in cash as an honorarium. Ten men participated in the focus group.

Focus Group One: Results

Ten men participated in the focus group. These men ranged in age from 55-87 years, with a mean age of 73.4. The age of the men was fairly evenly distributed by decade.

Content analysis of the focus group transcripts was conducted. Following the approach used by Vuckovic, Ritenbaugh, Taren, & Tober, ²⁴ transcripts were coded to index categories of responses. The transcripts were independently coded by the investigators and were checked for accuracy against notes taken during the focus groups. ²⁵ The coding process provided a systematic approach to identifying themes in the data. ²⁶ Statements identified from the data were open coded and grouped into conceptual categories, themes or axial codes by consensus among the investigators. ²⁶⁻²⁸ Themes related to survey questions that were common across both focus groups were identified, as well as themes unique to a particular focus group. The focus group data analysis revealed the following themes. Comments related to each them reflect statements made by unique individuals. Multiple comments by the same individuals are not included as separate statements.

Themes emerging from Focus Group 1 are shown in the Table 11. This table shows that these themes include motivation to participate in developing the survey and experiencing symptoms as motivation for previous cancer screening.

Themes shown in Table 11 also include the social support and influence factors of the importance of transferring health information intergenerationally in families and encouragement by others as motivation for cancer screening.

Cognitive/psychological factors shown in Table 11 include the perceived benefits of cancer screening, belief in the efficacy of early detection as motivation for cancer screening, fear as a barrier to cancer screening, lack of belief in provider efficacy, belief in provider efficacy, lack of belief in the accuracy of cancer screening tests, belief in the accuracy of cancer screening tests, knowledge/awareness of actions screening produces abnormal results, seeking knowledge as motivation for previous cancer screening, lack of knowledge regarding cancer screening tests, lack of

knowledge regarding cancer, knowledge regarding cancer, knowledge of diet as a cancer risk factor, lack of association between cancer screening and homosexuality, associating cancer with age, associating cancer with stress, discomfort of procedures as a reason not to get screened and knowledge of the use of PSA tests for cancer surveillance.

Programmatic/systemic factors shown in Table 11 include the role of health care providers, the role of health care settings, the role of computerized medical records, the role of health insurance coverage and the need to work to earn money, which may preclude having time available to participate in cancer screening activities.

Table 11. Themes Emerging from Focus Group 1

Theme	Comments Related to the Theme
Motivation to participate in developing the survey	 "Well, I think this (focus group) is one of the best things that could ever happen. Because I had been knowing about this (issue of cancer in African American men) for years. I did twenty-two years at Hospital as a physical therapist. And I have sons and grandsons, and I want to be able to help them" "Well, I have had the colon cancer test, and I have had the prostate cancer test, so everything was good in that area so now I still want to know more. I even have books at home about it (cancer), and I went to the health food store yesterday and they gave me a couple of magazines and I went through them and one of them was talking about cancer, too. And it is not always women who have cancer"

Theme		Comments Related to the Theme
Experiencing Symptoms as Motivation for Previous Cancer Screening		"Well what caused that is I was having bleeding in my rectum. And that was one of the reasons why I was bleeding in my rectum"
		"When they went into my rectum and screened my lower intestines, they couldn't find out what the cause of the bleeding was so they just told me to leave the popcorn and peanuts and seed and whatever leave them alone because I had gastritis So then they went through that and then the next time I had to go in and have a colon test and I was kind of upset about that one. And I went into that one and they did the same thing but instead of going into the lower part they went into the upper part. So they checked the upper part and they showed me the pictures and it was all right"
	0	"This April I will be 88 and years ago after I left Hospital, I had this urging to go to the bathroom, I did not know what was going on and the last time the urine would not flow. And when it did a clump of blood came out. Then I went to Hospital, and after that I was alright"
		"When speaking in terms of problems with urination and actually, as many of us get older, we have these particular problems but many times it is simply just an enlargement so far as the prostate. What happens is that you are squeezing and you can't get it out and it really is a problem. And I went in for this particular condition but you don't know whether or not it is cancer or whether or not it's just an enlargement. So you need to get that examined. For me, that was the case and for me, it was just an enlargement. So the route we went is Roto Rooter. They put you to sleep, and it's all dead down there and you don't feel anything. And after, then it's beautiful to be able to relieve yourself and you can"
		"I cannot imagine myself just walking into a doctor's office and saying, 'I don't have any symptoms but would you check me for something?' I just couldn't imagine myself doing that"

Theme	Comments Related to the Theme
Experiencing Symptoms as Motivation for Previous Cancer Screening (cont'd)	"My experience was I had always gone through the digital thing, and my doctor knew I had hemorrhoids, and do the smear thing. It (the test result) came in and it had a little bit of blood on the smear and he (the doctor) said, 'I know you've got hemorrhoids and that could be from that, but I want you to take this scope thing just to be sure, you know because it may be some cancer.' And that is all he had to say, you know that it could be, and you know it was no question I was going in to get that test" Likelihood of following doctor's suggestions to get screened: "You know, it depends on why he is saying that. Is he saying that he suspects that you have cancer, it's a possible cause, or is he saying it because maybe it's his policy to tell all his patients to get screened for cancer? (If the latter is true) I would do it, I might or might not But if he told me that my PSA was elevated and I better go see, I would go under those circumstances If he pointed out to me that your white blood cells count is ten times abnormal, then go see if you got leukemia. Then I would go get a test"
	"If I have symptoms, if he (doctor) says do this (get screened for cancer) because of something (symptoms), yes (I would get screened); if he says I don't have any specific reason (for suggesting screening) then I might or might not (get screened)"

Theme	Comments Related to the Theme
Social Support and Influence	"Awareness, they got to have elder people more educated
Factor: Importance of	(about cancer screening) and let them take care of the
Transferring	young ones (getting screened for cancer)"
Health Information	"If you can get it through the older peoples minds, to be
Intergenerationally	tested, (such as) for diabetes then maybe they would put
	it down to the little children and take them and have them tested It (raising awareness through churches) works;
	it works to get the message out"
	"You see, I had three heart attacks. My son came to me
	when he had to go in and have one of these tests (for his
	heart), and he asked me what did I have to go through for
	this test. And I sat down and I explained it to him how
	this test comes about. So when he went into the hospital
	and when they wheeled him into the operating room, I
	was there, and I told him do exactly what they tell you
	and you will come out all right. And he did and he came out all right"
	(Information about cancer symptoms described at
	church): "Right, because if they (the family) are looking at the pew and somebody just got up there and said, in
	other words describe if these things (cancer symptoms)
	are happening to you, the family is looking, in other
	words, that brings the family in and its going to touch
	something in that house"
	Because they will discuss it at the dinner table"
	"When we were talking about the family we were talking
	about us talking with our children. I was thinking just the
	opposite. If one of my daughters tells me, 'Dad, you are
	looking kind of peaked, you need to go in and get
	checked', you know, that would encourage you much
	more than if my mother said, 'Have you been checked
	lately?'. And I experience with my mother this last year,
	she was really sick and I was telling her, 'You need to go
	to the doctor', and she didn't want to listen to me, but as
	soon as my daughter said, 'Granny, you need to get to the
	doctor', she (mother) was putting on her coat to go,
	because she knew that she needed to go. So maybe your
	public service announcements would say, 'Have you
	looked at your parent?'. We've got an aging society now. 'Have you looked at your parents, are they getting
	tired'?"
	uicu :

Theme		Comments Related to the Theme
Social Support and Influence Factor: Encouragement by Others as Motivation for Cancer Screening	0	"So what made me do these things (getting screened) is that I have a member in my parish he has cancer and he told me 'Whatever you do, you go in and have them check you out for rectal cancer and your colon'. So I said whenever I go see my doctor I will put it (cancer screening) on her mind" "I am in the Disabled American Veterans office and
	0	some of those guys we have to drag them down there (to get screened) and threaten them, you know they don't want to go (to get screened)" "We get warnings all over TV (regarding the need for cancer screening) and pretty soon you don't pay it any attention. I think in order to get some reaction you have got to be able to relate to that person and their own frame of reference, you know in order to get their attention, not just some well know person on TV"
		"How about (raising) awareness through the churches? That information would be important(knowing whether) there is a greater possibility of you getting cancer because you are blackif you had a black man (saying this)" "there is an effective way and that is the publicity. When people began to die with lung cancer, look at what they started doing to the cigarette companies, to the tobacco companies. They've got every conceivable kind of advertisement about what smoking too much will do, they've even got it on the pack. In Canada they've got pictures of cancerous lungs. They are going to put that on a cigarette pack because smoking causes cancer It (negative publicity) is effective; look at the number of
		people who stopped smoking Think about (how if)every time you bought a pack of cigarettes, on the outside of the pack is a picture of a diseased lung" "I think it is the type of message you get out that would affect me. If there is a message that just says go and get checked every year, that probably would not affect me, but if the message was out there, these are the symptoms, there is a symptom that I can associate with, then I would go and ask for that test"

Theme	Comments Related to t e Theme
Social Support and Influence Factor: Encouragement by Others as Motivation for Cancer Screening (cont'd)	"Just like he (another participant) was saying before, somebody who we know has had the disease, come back just like Claude Young (the former Mayor's cousin, who is a physician), we all know him, (we would) all listen to him and say, 'Hey, we'd better check this out'"
	"Personally I think it (cancer screening) is a personal discussion and you have to talk to them one on one I think that the idea was brought up before that the TV is a very good way to do that"
	Disagreement:
	"I know, and everybody in this room knows the stats, that black people get cancer, prostate cancer, so what more can you do, because we all know that and you are right back to square one"
	"Putting someone up there to say, 'Black men or African American men have cancer 50% more (than Caucasian men)' is not going to do anything for me. But if he (someone) gets up there and says, 'I have to get up and urinate three times a night, you need to get this checked out, or do you have a burning sensation, do you have some blood in your stools, you better go get checked out' (would motivate him to get screened)"
	"You don't have to have somebody out there that is well known to do that (describe cancer symptoms)"
	"it (describing cancer symptoms) would bring about a better awareness (of the need for cancer screening)"

Theme		Comments Related to the Theme
Cognitive/Psychological		"It (screening) puts your mind at ease. The relief"
Factor: Perceived Benefits of		"The piece of mind"
Cancer Screening		"The quality of life"
		"Longer life but for that it is just the pleasure of being
		able to urinate. Some of these things you take for
		granted until you can't"
Cognitive/Psychological		"I have seen people who have waited too long (to get
Factor: Belief in the Efficacy		screened for cancer) and really suffered"
of Early Detection as		"In relationship to people not coming in or being afraid
Motivation for Cancer		to come in for a particular test because the fact that they
Screening		might have cancer, again we are talking in terms of if
		they are well aware of the fact that the sooner they come
		when they have cancer, the sooner it is taken care of, the
		sooner they might get well and the longer it takes for
		them to get in, they may die from it (cancer). Again, if
		they have that kind of information why should they be
		afraid to come in? They should be afraid not to come in
		(to get screened)"
		"I don't want to get to the symptoms; I want to know
		before I get the symptoms"
	п	"You know, anybody that has had a family members
	_	suffer, die from cancer I believe will be very reluctant to
		go to a doctor and say 'I want to be tested for
		cancer'But then there are an awful lot of people who
		have seen people suffer like I saw my father suffer, who
		are very reluctant to find out that they have such a
		disease as this. You know they have other diseases and
		won't go to the hospital or doctor It didn't make me
		feel reluctant (to get screened), but I became more afraid
		of whatever happened to me it must be cancer people
		who have seen suffering like that, they are very reluctant
		because they don't want to suffer"
	0	"Now I have just the opposite opinion about being afraid
	_	to go (to get screened for cancer). I worked with a guy
		- ' -
		maybe twenty years who thought maybe he had a peanut
		caught in his throat and turned out to be cancer, so with
		me now every time something happens or I feel
		something is not there I want to get it checked out just
		the opposite and just to make sure that I don't have or I
		can start my treatment early so I guess I don't understand
		why someone would be afraid to go in a get checked out
		if they got it they got it so better to find out and get some
		treatment than to just suffer with it"
		"I am definitely afraid of that sigmoid(oscopy), I tell you
		the truth. I have already avoided it"

Theme		Comments Related to the Theme
Cognitive/Psychological		"A lot of people are talking about being afraid of that
Factor: Belief in the Efficacy		scope for colon cancer"
of Early Detection as		"I don't have a problem with blood tests, and x-
Motivation for Cancer		raysyou know, that stuff doesn't bother me but the
Screening (cont'd)		sigmoid(oscopy), that's terrifying. What I am trying to
		say is if somebody, some inventor, could come up with
		something that could make that (colon cancer screening)
		easier, or they could put you to sleep or something, that would be much better"
		"I was apprehensive about that (sigmoidoscopy), but I
		asked that doctor this one question. I said, 'How long is
		it?' He told me so many centimeters, I said no, no in
		feet, he said 2 ½ feet. He said you would hardly feel it"
Cognitive/Psychological		"Now one of the things that I found out is that a lot of the
Factor: Lack of Belief in		doctors do not, cannot diagnosis cancer and we go to
Provider Efficacy		these people and they will tell you that maybe there is
		something else wrong, and you will be treated for
		something when you really have cancer"
	_	((7.1.1
	_	the first one I had, I had a little abrasion that came from
		the way the instrument was used, so I had a little sore
		spot, well it got well, but I have a tendency to think that
		when you are taking these tests, is the technician
		whoever is doing them, are they doing their job, correctly
		and as far as first aid, are they using good hygiene? This
		is the only thing I seem to worry about"
		"Now the medical journal stated that ham wasn't good
		for the African American person. Then they turned
		around from two weeks to a month later and they said
		there was nothing wrong with the African American
		eating ham, as long as it is lean. Now they turned around
		one time before and said salt was against the African
		male people, then they turned around and they changed it
		and said you can use salt, but a ¼ of a teaspoon. You see
		so when they go through those type of changes with you,
		they make you think, 'Why I am over here in the rehab.
		center going through these various lectures?' I told one
		of the physicians over there 'Now look, now you people
		go by what the American Journal says and then you take
		and translate it over to us what you want us to know'.
		Well I'm going to tell you something I can eat me a
		big spoon of whatever there is to eat and let that do me"

Theme		Comments Related to the Theme
Cognitive/Psychological		"He (a patient) will go in and maybe the doctor will see
Factor: Lack of Belief in		and maybe he won't even catch it (cancer) the first time"
Provider Efficacy (cont'd)		"I'm sure that everybody here has had a doctor who will
		tell them what they want them to know and no more"
Cognitive/Psychological		"That is the only reason I got it (received a PSA test due
Factor: Belief in Provider		to doctor's recommendation for the test)"
Efficacy		"My doctor just suggested that I get it (a PSA test). She said it was something new"
	Lil	kelihood of following doctor's suggestions to get screened:
		"All the way"
		"Would I follow-up? I certainly would"
		"I've been to my doctor and my doctor has said, 'I think
		it is time for you to do a test', and if he says it's time for
		me to do the test, I am going to do the test. But if he
		said, 'You don't have any symptoms or anything but I
		just think that it's time that you do it (get screened), I'm
		going to take the time and do that test, because he has
		some reason for saying this. And if I didn't trust him I
		would find another doctorOh, yeah (person indicated
		that they would take time off work to follow doctor's
		suggestion to get screened)"
		Well, I tell you my physician, she's on the ball every tine
		I go to her. In fact she is a member of my church. So if
		she doesn't see me on Sunday's she'll see me on
		Monday's. So I don't have any qualms with her she
		makes sure that I have all of my tests. I am under this
		new medication she put me under and this new
		medication has a diet to it she keeps me pretty well up
		to date with all of my tests"
Cognitive/Psychological		"I was wondering what good it would even do to test for
Factor: Lack of Belief in the		cancer. Some cancers you can test for and some you
Accuracy of Cancer Screening		can't. Some are only evident when you have
Tests		symptoms You know there is a problem with prostate
		cancer, because now they are saying that even if find
		prostate cancer, it doesn't make a difference, people who
		are treated for it and people who are not treated for it die
		at the same rate"

Theme	 Comments Related to the Theme
Cognitive/Psychological	"They've got to follow-up to see how accurate it (the test
Factor: Belief in the Accuracy	result) is"
of Cancer Screening Tests	"No (the tests are not pretty accurate)"
	"They only give you an indication and then you have to
	go in and take a biopsy
	"My grandson, they (doctors) said that he was cured,
	and then they had to call him back to take some more
	tests. He had the chemotherapy, they gave him his
	chemotherapy again. He told the nurse, 'Is this the last
·	one, because I've got to go to work, I've got to eat'my
	question is when they give you this chemo, I mean it's
	not perfected yet, see, to the extent where they can say
	you are cured, that is what I am talking aboutYou see,
	we are at the mercy of the doctors and the technicians.
	When they give you tests ,whatever procedure it is, and
	the results are read back to us, we listen (but) how can we tell whether it is accurate or not accurate, you know
	until we get too sick or in other words we would have to
	have something physical or something happen to us that
	is not right for us to say that that test wasn't too good"
a m	
Cognitive/Psychological	"Now if you check and find out and actually find out that
Factor: Knowledge/	symptoms do actually arise, what do you do, go see your
Awareness of Actions if	physician?"
Screening Produces Abnormal Results	
Results	
Cognitive/Psychological	"I have to make an observation there, because you got to
Factor: Seeking Knowledge as	face it, you never know what it is going to be like unless
Motivation for Previous	you go someplace and get it checked out"
Cancer Screening	
Cognitive/Psychological	"I guess I never associated the DRE test with checking
Factor: Lack of Knowledge	 for any kind of cancer there. I thought he was checking
Regarding Cancer Screening	for something else. Every time I go for an exam he (my
Tests	doctor) does that (a DRE), then he suggests doing the
	PSA even after that, so that is why I thought it was
	different"
	"Like he said, I had them go up in my rectum when I was
	young, I was about 22. I had that type of test, but this
	PSA test, I don't know whether the doctor gave me that,
	but I get my (physical) examination every year"
	The same of the sa
	 (doctors) determine lung cancer?"

Cognitive/Psychological Factor: Lack of Knowledge Regarding Cancer "I believe that (TB) was a form of lung cancer in the days before they really identified it. TB was a common cause of death, but actually that (TB) is cancer isn't it?" "Yeah, so is cancer?" "At the beginning of the last century on a basis of one to ten cancer is very low on the list of fatal diseases now I think it is about number 2 not that there are fewer people dying with cancer but I think the medical profession has honed in on some of the others?" "It is, eating away the tissues. I thought that is what cancer does?" "Cancer is a growth, an abnormal growth. An abnormal growth of cells" "Yeah, it destroys the healthy cells" "Yeah, it destroys the healthy cells" "We are generally here all past the year, the stage when prostate starts, and after 40 years of age, that's when you'd better start to look at it. Now if you know what the prostate does and what it is, it helps fertilize the egg for reproduction. And I guess everybody knows how it is situated in the body, and what happens when it (cancer) first begins to squeeze the tube that brings the urine from the bladder, and the urine can't get through there, and after 40 years of age, some people can pass it over and skip it and some don't but usually that's the time when you should be concerned (about prostate cancer)" "Our diet for African American men is one of the worst things there is. We say the same old thing, 'I know I'm not going to have it, but I just want a little piece'. A little piece of that ham, coconut cake" "When I was in the service they gave you that test; I never thought of that (homosexuality), I just hated the idea of somebody doing it" "That's what I wanted to addressI think 90% of that is psychological "It is the technician that does the work. Being sexually orientated in the wrong way, it is hard for you to do anything about that. That's up to the employer. See I am coming in to a physician to be waited on for some ailment, I not going to but the technicia	Theme		Comments Related to the Theme
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orientated in the wrong way, it is hard for you to do anything about that. That's up to the employer. See I am coming in to a physician to be waited on for some ailment, I not going to put the technician under			• •
anything about that. That's up to the employer. See I am coming in to a physician to be waited on for some ailment, I not going to put the technician under		-	
coming in to a physician to be waited on for some ailment, I not going to put the technician under			
ailment, I not going to put the technician under			

Theme		Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Association Between Cancer Screening and Homosexuality (cont'd)	0	"It's hard for you to observe" "You can observe, they've got a TV monitor up there. I saw it when they were going up in me. And what can you do about it? You can't do a thing about it but sit there and look (as the procedure is being done)"
Cognitive/Psychological Factor: Associating Cancer with Age		"I think that a lot of the organs can't fight off like they used too (as they age). A lot of medicine we can't take because your doctor says it is interfering with another medicine you are taking this medicine here is supposed to help take care of the cancerous cells, but you can't take it because like me you are taking your diabetic medicine"
Cognitive/Psychological Factor: Associating Cancer with Stress		"See I'm not a doctor but I could be a doctor because every time a black man would come into my office, you know what I would tell him? What every doctor tells a black man, first of all we got a little tiny bit of sugar, you got high blood pressure, and we see a little something there. But we're in the United States and we are going to have that stress factor. You were so glad years ago when you got one of the worst jobs wherever you went, you were glad to get it, you got the job you talk about stress, that is one of the symptoms, that brings about prostate cancer"
		"He's right about the amount of stress. That could be one of the causes (of cancer), it (stress) is built up over the generationsI think a lot of us men and I am sure women know that during the time as far as affirmative action on the job I know I came up and I knew my job well, you get in there but you are always under a microscope. You knew somebody was always standing near you. So with that type of stress you know you get off work and you go home and you have family life but sometimes some of that gets to you, you know. It's an everyday thing and I worked 30 years before I retired, you know what I mean. In 30 years it was day to day stress, you know somebody was out to get you, or trying to get to you and I know it, because I knew my job 4 times better or five times better than my co-workers did. But the point is there was always somebody up there trying to put you down. So I'm just trying to tell you about the stress factorI'm saying it was real I don't think anybody in the room can sit here and say that they didn't have day to day stress, unless you were working for yourself, then the stress level was worse, but it was a different kind of stress"

Theme		Comments Related to the Theme
Cognitive/Psychological Factor: Associating Cancer with Stress (cont'd)	0	"I had a black out. My blood pressure went up so high and I had a black out and everything turned black and the next day I went up there and signed for retirement" "Now we talking about the playing field, you take
	_	economics come in there too. Just like he mentioned the post office, I started at the post office \$1.31/hr and I couldn't take care of my family. I mean a two week check come, I know what I had coming. And I got my check and it was \$232 that was a two-week check. Twelve hours a day, and I just felt like crying I had six babies at home, I had to go to and get me a better job"
Cognitive/Psychological Factor: Discomfort of		"The uncomfortableness of the procedure (kept him from getting screened"
Procedures as Reason Not to Get Screened	0	"Yeah, just like he said, knowing that someone is going to be going up your rectum, just the thought of it I guess. Unless you just have to go in there, you are not going to go. So, sometimes you wait too late which is ultimately what is going to have to happen"
Cognitive/Psychological Factor: Knowledge of the Use of PSA Tests for Cancer Surveillance	•	"The PSA is just a follow-up, you know when they do that rectal test it is what ever his opinion is but to actually tell you if it is cancer that is really, not really dormant we say the PSA test lets you know what level it is, that is the real test. Once you get prostate cancer, you get a procedure or something the PSA test you go in for every six months or whatever the doctor say to see if it is maintaining the same level and that is how they monitor a person who has prostate cancer"

Theme		Comments Related to the Theme
Programmatic/Systemic Factor	_	"When you are going through the procedure, you can
Related to Cancer Screening:	u	analyze these techniques and you know when the man
Role of Health Care Providers		does a good job. You know he does a good job when he
Role of Health Care Floviders		gives you awareness or this or that, it is a job well done"
	_	"I think in all these cases you are talking in terms of the
		•
		person comes in and it is adequately explained what is
		going to happen and how it is going to happen and what
		procedure and precautions have been taken previously
	_	for that particular procedure" "You said your friend (who died of colon concer) come
		in (to the health system) for a physical every year. Can
		you explain why when the person came in for a physical
		that the people that gave them that physical didn't
		include tests for colon or prostate cancer? Some of these
		things you can just discover by giving them a test"
		"When you are going through the procedure, you can
		analyze these techniques and you know when the man
		does a good job. You know he does a good job when he
		gives you awareness or this or that, it is a job well done"
		"I think in all these cases you are talking in terms of the
		person comes in and it is adequately explained what is
		going to happen and how it is going to happen and what
		procedure and precautions have been taken previously
		for that particular procedure"
		"You said your friend (who died of colon cancer) came
		in (to the health system) for a physical every year. Can
		you explain why when the person came in for a physical
		that the people that gave them that physical didn't
		include tests for colon or prostate cancer? Some of these
		things you can just discover by giving them a test"
		"And when I was looking at this purpose of this study, it
		is really to see if you have a procedure or a standard way
		that people should be going in for physical exams, and
		when they go in for a physical exam do they (health care
		providers) test for the things"
		"now when you said that your doctor should do it
		(screen for cancer periodically), now if you have a
		care person, you have your medical record, now your
		physician, each time you go see your physician, your
		physician goes through these records supposedly, now
		sometimes you have to make sure that they go through
		these records. But if they go through these records and
		you have these various test, they know when you are due
		for your next one"

		Community Deleted to the Thomas
Theme		Comments Related to the Theme
Programmatic/Systemic Factor		"(But) you may be going to different doctors. When you
Related to Cancer Screening:		go to one doctor they have one record and you go to
Role of Health Care Providers		another doctor, he's got a record, and they don't have
(cont'd)		access to the previous records"
		But you go to the doctor, I don't know what the
		experience is, but I have seen time and time again,
		doctors today keep fighting the HMO's. You go to
		doctor and he will give you ten minutes, he does not have
		time to give you the examination or screening
		examination. I go to doctors all the time because I am
		not well. I don't have a heck of a lot of time; I was going
		down to Cleveland Clinic because that was the only place
		I could go where they gave me enough time to see what
		was wrong with me"
		"(A) periodic check-up (should take place) every six
	_	months for people that are 65 or older. In other words,
		you go in and schedule yourself for a physical and that
		physical that you are going to be scheduled for is going
		to target certain things in that age group, and that is what
		you go in for and the doctor says, 'Ok, then, you are
		fine. Come back and see me in six months or
		so'That's what needs to happen. If they establish a
		profile in the department they have a bunch of people
		that have been trained to do this, that is when it comes
		out. And if that patient ignores that check-up then no
		better for them"
		"I know at my doctor's they make you fill out this
	_	postcard in your own handwriting so that when it is close
		to time for your appointment, you get this postcard in the
		mail. It makes them and you aware of the fact that you
		have an appointment"
·		"if you go to a doctor or a hospital he (the doctor) is
		not going to initially test you for whatever and see if you
		have cancer(provider never suggested that he get
		checked for cancer) No, not cancer specifically, but I
		wanted it after I saw what happened to my father. He
		was the first to die of cancer. And I went for it
		specifically"
Programmatic/Systemic Factor		"And if you talk in terms of how can the health
Related to Cancer Screening:		community help whether instead of just coming into the
Role of the Health Care Setting		hospital just sitting there waiting, rather than watching
		your sitcoms on television, why not have some
		educational information there for them (patients who are
		waiting to see the doctor)"

Theme		Comments Related to the Theme
Programmatic/Systemic Factor		"I believe that there should be a department or specialist
Related to Cancer Screening:		set-up to review medical records as a form of screening
Role of Computerized Medical		to recommend (patients for screening), like a big hospital
-		like Hospital, they should have someone to review
Records		medical records and you know there is a certain profile that you could pull out and you know someone like you (moderator), can study it I am talking about a special departmentIt's just that the medical records document everything and people, say our age, when they go in for, some way to trigger someone to screen it, to really go down through this and say this person has never been tested for colon cancer, prostate cancer, but all the symptoms of all these other reasons they have been going to see the doctor over the years is right there in your medical records. So they will evaluate, personally evaluate this (each patient's need for cancer screening). It could be a doctor or medical research, but the point is not to wait for that person to get half dead to come into the hospital (due to symptoms related to cancer) So they (the patient could then) come in and get a biopsy as opposed to that person, having problems going to the bathroom or something, (because) there is a blockage or
		"When I go in they will check me; I kind of wish they would send me like reminders of something to do, which they do not dobut what if I am not being treated for anything, and that is why I don't get there every year, because I don't think about it every year. Years have gone by before I think about it (getting screened for cancer) and then it is another 6 months before I make the appointment (to get screened)"
	0	"The reminders are usually when you are being treated (rather than screened), and you do great"
		"Like dentists do that; they find out you have good dental insurance and they make sure that you get a notice (for a return visit). Man, those dentists are right on the kicker"
		"It seems like that could be computerized, with just your name and age"
	0	"You should get a notice from your doctor and they will send you a reminder"

Theme		Comments Related to the Theme
Programmatic/Systemic Factor Related to Cancer Screening: Health Insurance Coverage	0	When you mean the time frame, every three years to get your colon, what controls that for it to be every three years, the doctor or your insurance coverage?" "Yes. I had that (sigmoidoscopy) done last year, so I have two more years to go before I go through it again"
	0	"If they got insurance and everything, the only thing that would keep them from doing it (getting screened for cancer) is that they got to dig in their pocket and pay that doctor a lot of money, but most of us got insurance" "If you take care of that car your transmission is not going to go bad. The motor is not going to go bad except I got to take the time to do that and I have got to do the same thing with my body. Except it is a lot cheaper to go in and get the (screening) test done than to wait until something really serious (is found)" "If you belong to an HMO, they (providers) are supposed to maintain health and the doctors are constantly dreading that"
Programmatic/Systemic Factor Related to Cancer Screening: Need to Work to Earn Money Precludes Time Available for Cancer Screening		"I have avoided that (a chest x-ray), too. Because sometime the overtime comes up and I needed money (and so did not have time to get screened for cancer)" "Is everybody here retired, except me? In other words, there is a difference between the retired guys and the guys that work The difference is that the guys who are retired can go to the hospital every day and the guys who work can't (because they do not have time to go)" "It's not a question of trust (of a doctor), it's that I have more of a priority (to work rather than to get screened)"

Tasks 2 (e) - (i): (e) Based on the focus group results, revise the measurement instrument. (f) Hold a focus group session to assess participants' perceptions of the revised measurement instrument. (g) Incorporate participants' suggestions into a further refinement of the instrument. (h) Conduct statistical analyses of the pilot study results. (i) Revise and refine the final measurement instrument, based on the pilot study results.

Methods used in the first focus group were used to identify a sample for the second focus group (Figure 1). In the second focus group, the 11 men ranged in age from 53-81 years, with a mean age of 68.7 years.

The survey items and wording were validated in the focus group. During the focus groups, cognitive/psychological factors of fear and anxiety regarding cancer diagnosis and lack of knowledge about screening tests and screening benefits were stated. Wives were noted as the most important social support and influence persons affecting screening behavior. Having a trusted health care provider and health insurance were cited as programmatic/systemic screening-related factors.

The survey that was evaluated (and is designed to be administered via telephone) and the moderator's guide used in the second focus group are included in the following paragraphs. This guide contains the set of questions used to elicit responses from focus group participants regarding their perceptions of the revised measurement instrument.

Survey Evaluated During Focus Group 2

(Survey Cover Sheet)

We are interested in your opinions about your health and the health care that you receive. All of the information that you provide will be kept confidential.

In this section of the survey, I will read some statements about your health and the health care that you receive. Please tell me whether you STRONGLY AGREE, AGREE, NEITHER AGREE NOR DISAGREE, OR STRONGLY DISAGREE with each statement.

	SAGREE, DISAGREE, OR STRONGLY D Pleaseadhir synether synthydie o'r				Negration	Strongly
	रविद्यालकार्यकृतिकार्याकार्यकार्यकार्यकार्यकार्यकार्यकार्	A. A		्रेश्वर्गः • रुवर्गः		Disagree
				, TO		
				Disappres		
a.	My quality of life would be better if I	Militaria di ministra di 1900 1900 1900 1900 1900 1900 1900 190	A	3	2	1
a.	was checked for cancer than it would be	3	•		_	-
	if I did not get checked for cancer.					
b.	I would get checked for cancer even if I	5	4	3	2	1
0.	had not been experiencing any symptoms		•		-	_
	of cancer.					
c.	Some people do not get checked for	5	4	3	2	1
\ \tilde{-}	cancer because they just never get around		•		_	-
	to it.					
d.	Embarrassment would keep me from	5	4	3	2	1
-	getting checked for cancer.		•			_
e.	Some people avoid getting checked for	5	4	3	2	1
	cancer because they are afraid to think	-				
	about cancer.					
f.	The results of cancer screening tests are	5	4	3	2	1
	accurate.					
g.	Some men associate certain tests to check	5	4	3	2	1
	for cancer with being a homosexual (a					
	man who prefers dating men).					
h.	Most people would have transportation to	5	4	3	2	1
	a health care clinic if they decided to get					
	checked for cancer.					
i.	People who have regular check-ups by a	5	4	3	2	1
	doctor should not worry about getting					
	cancer.					
j.	Exercising regularly affects your chances	5	4	3	2	1
	of developing cancer.					
k.	Being older affects your chance of	5	4	3	2	1
-	developing cancer.					
1.	Cancer runs in families.	5	4	3	2 2	1
m.	African American people are more likely	5	4	3	2	1
_	than other people to get cancer.	5	4	3	2	1
n.	Poor people are more likely than other	ז	4	3	2	1
_	people to get cancer. I have a reduced risk of getting cancer,	5	4	3	2	1
ا ^ن	compared to other men my age.	ر ا	4	3		1 1
-	I have the same risk of getting cancer,	5	4	3	2	1
P.	compared to other men my age.	, ,	7		2	1
q.	I have a greater risk of getting cancer,	5	4	3	2	1
A.	compared to other men my age.		-7			
	compared to outer men my age.					

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r.	Eating foods in high in fat (or a high fat diet) affects your chances of getting cancer.	5	4	3	2	1
S.	It is possible to have cancer without having symptoms of this disease.	5	4	3	2	1
t.	If cancer is found early enough, it can be cured.	5	4	3	2	1
u.	I know the possible side effects of cancer treatment.	5	4	3	2	1

Now I will ask you some other questions about your health and the health care you receive. Again, we are interested in your opinions.

2.	What words would you use to describe cancer?	
3.	Do you know someone who has had cancer?	[1] Yes [2] No
4.	Have you ever heard of a PSA test?	[1] Yes (Answer q. 5) [2] No (Skip to q. 6)
5.	How would you describe this test?	
6.	Have you ever heard of a chest x-ray?	[1] Yes (Answer q. 7) [2] No (Skip to q. 8)
7.	How would you describe this test?	
8.	Have you ever heard of a flexible sigmoidoscopy?	[1] Yes (Answer q. 9) [2] No (Skip to q. 10)
9.	How would you describe this test?	

10. What do you think are some of the early warning signs of cancer?	
11. Do you think that people who have had cancer in their family are more likely than other people to get cancer?	[1] Yes [2] No
12. Do you think that people who have had cancer in their family should get checked for cancer more often than someone who does not had cancer in their family?	[1] Yes [2] No
13. Do you have any fears and/or concerns about prostate cancer screening? (IWER, please read: cancer screening means getting checked for cancer before a doctor has told you that you have cancer.)	[1] Yes [2] No (Skip to q. 15)
14. Could you please describe some of these fears and/or concerns?	
15. Do you have any fears and/or concerns about lung cancer screening?	[1] Yes [2] No (Skip to q. 17)
16. Could you please describe some of these fears and/or concerns?	
17. Do you have any fears and/or concerns about colorectal cancer screening?	[1] Yes [2] No (Skip to q. 19)
18. Could you please describe some of these fears and/or concerns?	
19. What do you think are the benefits of prostate cancer screening?	
	[1] None (Skip to q. 21)
20. Would these benefits motivate you to get checked for prostate cancer?	[1] Yes [2] No
21. What do you think are the benefits of lung cancer screening?	
	[1] None (Skip to q. 23)

22. Would these benefits motivate you to get checked for lung cancer?	[1] Yes [2] No
23. What do you think are the benefits of colorectal cancer screening?	
24. Would these benefits motivate you to get checked for colorectal cancer?	[1] None (Skip to q. 25) [1] Yes [2] No
25. Do you think that people can be cured of prostate cancer?	[1] Yes (Answer q. 26) [2] No (Skip to q. 27) [3] Don't know (Skip to q. 27)
26. Do you think that people who have been cured of prostate cancer can live a normal life?	
27. Do you think that people can be cured of lung cancer?	[1] Yes (Answer q. 28) [2] No (Skip to q. 29) [3] Don't know (Skip to q. 29)
28. Do you think that people who have been cured of lung cancer can live a normal life?	
29. Do you think that people can be cured of colorectal cancer?	[1] Yes (Answer q. 30) [2] No (Skip to q. 31) [3] Don't know (Skip to q. 31)
30. Do you think that people who have been cured of colorectal cancer can live a normal life?	

In the next section of the survey, I will read some statements about sources of health information. Please tell me whether you STRONGLY AGREE, AGREE, NEITHER AGREE NOR DISAGREE, DISAGREE, OR STRONGLY DISAGREE with each statement.

The Algerta colors of the first of the colors of the color	Shongly - १५७७		1))सम्बद्धः राज		Strongly Disagree
I can learn more information about cancer	5	4	3	2	1
through:					
a. Booklets or pamphlets	5	4	3	2	1
b. Flyers	5	4	3	2	1
c. Radio ads	5	4	3	2	1
d. Television ads	5	4	3	2	1
e. Newspaper ads	5	4	3	2	1
f. Church bulletins	5	4	3	2	1
g. Magazine ads	5	4	3	2	1
h. Billboards	5	4	3	2	1

For the next set of statements, please tell me how much being encouraged by a spouse, a church member, a member of a club or by relatives and friends would influence your decision to get checked for cancer. Let's start with being married. (Read Statement a.)

	ានខ្មែលក្នុងស្រែចម៉ាល់ស្រាកែកសាស្រែបម្រក សេចកាមាល់ ការប្រធានទេសហគ្រាស្រីកីសសាមការជនការប្រកិច្ច ការសុខក			Some phác	
a.	To what extent would being encouraged by your spouse influence your decision to get checked for cancer?	4	3	2	1
b.	To what extent would being encouraged by your minister influence your decision to get checked for cancer?	4	3	2	1
c.	To what extent would being encouraged by members of a club (Masons, fraternity, etc.) influence your decision to get checked for cancer?	4	3	2	1
d.	To what extent would being encouraged by relatives and friends influence your decision to get checked for cancer?	4	3	2	1

Now I will ask you some other questions about people in your life who play a role in your decision to get checked for cancer. 33. Which of the following people have [1] Minister or church members [2] Club members (masons, fraternity, etc.) influenced your decision to get checked for prostate cancer? (Circle all that [3] Daughter apply) [4] Father [5] Mother [6] Other family member(s) [7] Son [8] Wife [9] No one [10] Other, please describe: 34. Are there people in your life with whom [1] Yes (Answer q. 35) you discuss prostate cancer? [2] No (Skip to q. 36) 35. What is their relationship to you? [1] Minister or church members [2] Club members (masons, fraternity, etc.) (Circle all that apply) [3] Daughter [4] Father [5] Mother [6] Other family member(s) [7] Son [8] Wife [9] No one [10] Other, please describe: 36. What do you think would help to motivate African American men to get checked for prostate cancer? 37. Which of the following people have [1] Minister or church members influenced your decision to get checked [2] Club members (masons, fraternity, etc.) for lung cancer? (Circle all that apply) [3] Daughter [4] Father [5] Mother [6] Other family member(s) [7] Son [8] Wife [9] No one [10] Other, please describe:

38. Are there people in your life with whom you discuss lung cancer?39. What is their relationship to you? (Circle all that apply)	[1] Yes (Answer q. 39) [2] No (Skip to q. 40) [1] Minister or church members [2] Club members (masons, fraternity, etc.) [3] Daughter [4] Father [5] Mother [6] Other family member(s) [7] Son [8] Wife [9] No one [10] Other, please describe:
40. What do you think would help to motivate African American men to get checked for lung cancer?	
41. Which of the following people have influenced your decision to get checked for colorectal cancer? (Circle all that apply)	[1] Minister or church members [2] Club members (masons, fraternity, etc.) [3] Daughter [4] Father [5] Mother [6] Other family member(s) [7] Son [8] Wife [9] No one [10] Other, please describe:
42. Are there people in your life with whom you discuss colorectal cancer?43. What is their relationship to you? (Circle all that apply)	[1] Yes (Answer q. 43) [2] No (Skip to q. 44) [1] Minister or church members [2] Club members (masons, fraternity, etc.) [3] Daughter [4] Father [5] Mother [6] Other family member(s) [7] Son [8] Wife [9] No one [10] Other, please describe:

44. What do you think would help to motivate African American men to get	
checked for colorectal cancer?	

The next set of statements are about your health care experiences. Please tell me whether you Strongly Agree, Agree, Neither Agree Nor Disagree, or Strongly Disagree with each statement.

	त्रभावत् अपिता क्षणात्रभावत् प्रयोक्षणात्रकारः त्रोक्षणाव्यस्य क्षणीति स्ति = () () () () () () () () () () () () () ()			Stelliter Averes Store Disagnes	Disagree	Strongly Disagree
a.	Fear and mistrust of the health system keep African Americans from getting checked for cancer.	5	4	3	2	1
b.	Embarrassment about the screening process keeps African American men from getting checked for cancer.	5	4	3	2	1
c.	Having a doctor influences people's decision to get checked for cancer.	5	4	3	2	1
d.	Having health care insurance influences people's decision to get checked for cancer.	5	4	3	2	1
e.	People choose not to get checked because they cannot afford treatment if cancer were found.	5	4	3	2	1
f.	Checking for cancer should be included as a part of a regular health care exam.	5	4	3	2	1
g.	Health care clinics are open at convenient times to allow people to get checked for cancer.	5	4	3	2	1

Now I would like to ask you a few more questions about your experiences with doctors and your access to health care.

46. Has your doctor ever talked to you about getting checked for prostate cancer?	[1] Yes [2] No
47. Have you ever been checked for prostate cancer?	[1] Yes (Answer q. 48) [2] No (Skip to q. 49)
48. Did you talk to a doctor after you were checked for prostate cancer?	[1] Yes [2] No
49. What do you think messages designed to encourage African American men to get checked for prostate cancer should say?	

50. Has your doctor ever talked to you about getting checked for lung cancer?	[1] Yes [2] No
51. Have you ever been checked for lung cancer?	[1] Yes (Answer q. 52) [2] No (Skip to q. 53)
52. Did you talk to a doctor after you were checked for lung cancer?	[1] Yes [2] No
53. What do you think messages designed to encourage African American men to get checked for lung cancer should say?	
54. Has your doctor ever talked to you about getting checked for colorectal cancer?	[1] Yes [2] No
55. Have you ever been checked for colorectal cancer?	[1] Yes (Answer q. 56) [2] No (Skip to q. 57)
56. Did you talk to a doctor after you were checked for colorectal cancer?	[1] Yes [2] No
57. What do you think messages designed to encourage African American men to get checked for colorectal cancer should say?	
58. Do you have trouble now in getting regular health care?	[1] Yes (Answer q. 59) [2] No (Skip to q. 60)
59. What are some of the problems you are facing in getting regular health care?	
60. Do you think that doctors and other health care providers should talk to African American men about their cancer risk?	[1] Yes [2] No (Skip to q. 63)
61. What do you think doctors and other health care providers should say?	

In the last section of this survey, I would like to ask you questions about your general background, work history and smoking history.

63. Which of the following best describes your race?	[1] African American or Black [2] American Indian or Alaskan Native [3] Asian [4] Caucasian or White [5] Pacific Islander [6] Other, please describe:
64. Is there another racial group with which you identify?	[1] Yes (Answer q. 65)
65. Which of the following best describes this other group?	[2] No (Skip to q. 66) [1] African American or Black [2] American Indian or Alaskan Native [3] Asian [4] Caucasian or White [5] Pacific Islander [6] Other, please describe:
66. Are you of Hispanic origin?	[1] Yes [2] No
67. What is your date of birth?	// mm/ dd/ yyyy
68. What is your gender?	[1] Male [2] Female

69. What is the highest grade of level of school that you have completed?	[1] 8" grade or less [2] Some high school, did not graduate [3] High school graduate or GED [4] Post high school training, other than college (vocational or technical training) [5] Some college or 2-year graduate [6] 4-year college graduate [7[Postgraduate (more than a 4-year college degree)
70. What is your current marital status?	 [1] Divorced [2] Living with a partner [3] Married [4] Married, but separated [5] Never been married [6] Widowed
71. Has a doctor ever told you that you have any of the following health conditions? A) Coronary Heart Disease/Heart Attack B) Cancer C) High Blood Pressure (hypertension) D) Diabetes E) Stroke F) Arthritis	[1] Yes [2] No
72. Did a doctor ever tell you that you have any other health condition(s)?	[1] Yes (Answer q. 73) [2] No (Skip to q. 74)
73. What are these other condition(s)?	

74. Please choose the response that best describes your employment		
status:	[[] V	[O] No (Amouson
A) employed for wages	[1] Yes	[2] No (Answer
B) self-employed	q. 75)	F0137 /A
C) out of work for ≤1 year and looking for work	[1] Yes	[2] No (Answer
D) out of work for >1 year and looking for work	q. 75)	
E) homemaker	[1] Yes	[2] No (Skip to
F) student	q. 76)	
G) retired	[1] Yes	[2] No (Skip to
	q. 76)	[.]
H) unable to work	[1] Yes	[2] No (Skip to
		[2] 140 (BMP to
	q. 76)	FOI NI - (Claim to
	[1] Yes	[2] No (Skip to
	q. 76)	
	[1] Yes	[2] No (Skip to
	q. 76)	
	[1] Yes	[2] No (Skip to
	q. 76)	
75. In an average week, about how many hours do you work on your		# of hours
job?		•
76. How many people live in your household, including yourself?		
	. £11 O	
77. Do you own or rent your home/apartment?	[1] Own	
	[2] Rent	
78. What is your monthly mortgage payment/rent?	\$	_
79. Have you ever smoked more than 100 cigarettes in your lifetime?	[1] Yes	
	[2] No	
80. Have you ever exercised at least 3 times per week?		Answer q. 81)
oo, have you ever energiable at least a mines per mount		kip to q. 82)
	[2]::0 (3:	
01 D	[1] Yes	
81. Do you exercise at least 3 times per week now?		
	[2] No	
Thank you for completing this questionnaire. Your opinions can help		
us to improve the health care we provide. To show you our		
appreciation of your time spent completing this survey, we will mail		
you a \$5 Blockbuster Video gift certificate. Would you like us to send		
you a copy of the survey results (Interviewer records participant's		
response)		
responsej	1	

Focus Group Moderator's Guide Perceptions of Cancer Screening

Facilitator: Marvella Ford Assistant: Danica Dixon Recorder: La-Kesha Parrish

October 26, 2000 6:00 - 8:00 p.m.

I. WARM-UP AND EXPLANATION (10 minutes)

A. Introduction

- Good evening. My name is Marvella Ford. I work here at Henry Ford Health System.
 This is Danica Dixon. She will be the assistant this evening. La-Kesha Parrish is our
 recorder. Danica and La-Kesha also work here at HFHS.
- 2. Thanks for coming.
- 3. Your presence and participation are important. Your thoughts and comments about the questionnaire will be valuable in helping to provide future information on health issues.

Purpose

- 1. What we are doing here this evening is called a focus group. It's a discussion to find out your opinions -- like a survey.
- 2. I am interested in all of your ideas, comments and suggestions.
- 3. Each of you is very important and all of your comments -- both positive and negative -- are welcome.
- 4. There are no right or wrong answers.
- 5. Please speak up -- even if you disagree with someone else here. It important that I hear what each of you thinks.

B. Procedure

1. We will be audiotaping and videotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later we'll go through all of your comments and use them to prepare a report on our discussion. However, all of your comments are confidential and will be used only for research

purposes. Nothing you say will be connected to your name. Also, if any questions make you uncomfortable, feel free not to answer them.

- 2. You don't have to wait for me to call on you but please speak one at a time, so the tape recorder can pick up everything.
- We have many topics to discuss so I may change the subject or move ahead. Please stop
 me if you want to add anything.

C. <u>Self-Introductions</u> (Ice Breaker)

I. Please tell us your name and describe the car of your dreams.

II. QUESTIONNAIRE

1. Please look at the first page of the survey.

Are the statements on this page clear?

If so, what makes these statements clear?

If not, which words would you use to make the statements clearer?

Now, please turn to page 2 of the survey.

Are the instructions on how to complete this table clear?

If not, which words would you use to give instructions for completing this table?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Now please look at questions (a) - (u) on pages 2-3 of the survey. Are these questions clear?

Which questions are clear?

What makes these questions clear?

Which questions are not clear?

What makes these questions unclear?

How would you ask these questions to make them clearer?

How comfortable would you feel about completing questions (a) - (u)?

What makes you feel comfortable or uncomfortable about completing these questions?

3. Now, let's turn to questions 2-10 on page 3.

Are any of questions 2-10 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 2-10?

If you think it would be hard, what would make these questions easier to fill out?

If you think it would be easy, what makes them easy to fill out?

Is it clear to you that if you answer "NO" to question 4, you should go to question 6?

Is it clear to you that if you answer "NO" to question 6, you should go to question 8?

Is it clear to you that if you answer "NO" to question 8, you should go to question 10?

How comfortable would you feel in answering questions 2-10?

What makes you feel comfortable or uncomfortable about answering these questions?

4. Now, let's look at questions 11 and 12 on page 4.

Are questions 11 and 12 clear to you?

If not, which words would you use to ask questions 11 and 12?

How comfortable would you feel in answering questions 11 and 12?

What makes you feel comfortable or uncomfortable about answering these questions?

5. Let's turn now to questions 13-24 on pages 4 and 5.

Are any of questions 13-24 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 13-24?

If you think it would be hard, what would make these questions easier to fill out?

If you think it would be easy, what makes them easy to fill out?

Is it clear to you that if you answer "NO" to question 13, you should go to question 15?

Is it clear to you that if you answer "NO" to question 15, you should go to question 17?

Is it clear to you that if you answer "NONE" to question 19, you should go to question 21?

Is it clear to you that if you answer "NONE" to question 21, you should go to question 23?

Is it clear to you that if you answer "NONE" to question 23, you should go to question 25?

How comfortable would you feel in answering questions 13-24?

What makes you feel comfortable or uncomfortable about answering these questions?

6. Let's turn now to questions 25-30 on page 5.

Are any of questions 25-30 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 25-30?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 25-30?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 25, you should go to question 27?

Is it clear to you that if you answer "DON'T KNOW" to question 25, you should go to question 27?

Is it clear to you that if you answer "NO" to question 27, you should go to question 29?

Is it clear to you that if you answer "DON'T KNOW" to question 27, you should go to question 29?

Is it clear to you that if you answer "NO" to question 29, you should go to question 31?

Is it clear to you that if you answer "DON'T KNOW" to question 29, you should go to question 31?

7. Now, let's look at the first table on page 6.

Are the instructions on how to fill out the table clear to you?

If not, how could they be made clearer?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Are the words in the table clear to you?

If not, which words would you use to describe these things?

8. Now, let's look at the second table on page 6.

Are the instructions on how to fill out the table clear to you?

If not, how could they be made clearer?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Are the words in the table clear to you?

If not, which words would you use to describe these things?

9. Let's turn our attention now to questions 33-44.

Are any of questions 33-44 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 33-44?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 33-44?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 34, you should go to question 36?

Is it clear to you that if you answer "NO" to question 38, you should go to question 40?

Is it clear to you that if you answer "NONE" to question 42, you should go to question 44?

10. Now, let's look at the table on page 9.

Are the instructions on how to fill out the table clear to you?

If not, how could they be made clearer?

How does the layout of the table look to you?

How would you feel if you were asked to complete this table?

Are the words in the table clear to you?

If not, which words would you use to describe these things?

11. Let's turn now to questions 46-61.

Are any of questions 46-61 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 46-61?

If you think it would be hard, what would make these questions easier to fill out?

If you think it would be easy, what makes them easy to fill out?

Is it clear to you that if you answer "NO" to question 47, you should go to question 49?

Is it clear to you that if you answer "NO" to question 51, you should go to question 53?

Is it clear to you that if you answer "NO" to question 55, you should go to question 57?

Is it clear to you that if you answer "NO" to question 58, you should go to question 60?

Is it clear to you that if you answer "NO" to question 60, you should go to question 63?

How comfortable would you feel in answering questions 46-61?

What makes you feel comfortable or uncomfortable about answering these questions?

12. Now, let's look at questions 63-70.

Are any of questions 63-70 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 63-70?

If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 63-70?

What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 64, you should go to question 66?

13. Now, let's look at questions 71-81.

Are any of questions 71-81 unclear to you?

If so, how would you ask these questions?

How hard would it be to fill out questions 71-81? If you think it would be hard, what would make these questions easier to fill out?

How comfortable would you feel in answering questions 71-81? What makes you feel comfortable or uncomfortable about answering these questions?

Is it clear to you that if you answer "NO" to question 72, you should go to question 74?

Is it clear to you that if you answer "NO" to question 80, you should go to question 82?

14. Now, let's talk about different ways the survey might be completed.

If the survey were mailed to your home, do you think you would complete it?

Do you think you would mail your completed survey back in a postage-paid envelope?

If someone called you to ask you the survey questions over the telephone, do you think you would complete it?

How would you rather complete this survey:

- 3. At home and return it in a postage-paid envelope?
- 4. Over the telephone with questions asked by a trained staff person?
- 3. In person with questions asked by a trained staff person?

III. GENERAL PERCEPTIONS OF HEALTH AND HEALTH SERVICES

Do you think that people who have regular check-ups by their doctor need to worry about getting cancer?

What makes you say this?

Do you have difficulty now in getting regular health care?

If so, what are some of the problems you are facing (Probe: waiting time to get an appointment; transportation problems; cost; time away from work)

Do you think that testing for cancer should be included as part of the physical exam done by your doctor?

What makes you feel this way?

Do you think that doctors and other health care providers should talk to Black men about their cancer risk?

(If yes, probe: What kinds of things do you think doctors and other health care providers should say to Black men about their cancer risk?)

Does your doctor talk to you about your risk of getting cancer?

(If yes, probe: What kinds of things does your doctor talk to you about, in terms of your risk of getting cancer?)

What could your doctor do to encourage you to get screened (or checked) for cancer?

(Probe: verbal recommendations and/or letters suggesting screening)

Do you think that health care clinics and hospitals are open at convenient times for cancer screening (or getting checked for cancer before you've ever had it)?

(If not, probe: What could be done to make the times more convenient for people to get cancer screening?)

Do you think that using t.v., radio, newspaper and magazine ads to encourage Black men to get screened (or checked) for cancer would be effective?

(Probe for reasons why or why not: Let's start with t.v. ads...Now, let's talk about radio ads.) (Probe: If men think ads would be effective say: What should these ads look or sound like? Who should be in them?)

How accurate do you think that the results of cancer screening tests are?

How likely do you think it would be for you to have cancer without having any signs or symptoms?

Do you know someone who has had cancer?

Do you think cancer can be cured if it is found early enough?

What makes you feel this way?

Do you think that people who have had cancer can live a normal life?

What makes you feel this way?

Do you think that your life would be better if you were screened (or checked) for cancer than it would be if you were not screened (or checked) for cancer?

(Probe: In what ways would your life be better? In what ways would your life not be better?)

How do you think that being African American affects your chances of getting cancer?

What do you think your risk is of getting cancer, compared to other men your age?

Thank you very much for your comments tonight. They were very helpful.

Focus Group Two: Results

Eleven men participated in the focus group. These men ranged in age from 53-81 years, with a mean age of 68.7 years. The age of the men was fairly evenly distributed by decade.

As with the data from Focus Group 1, content analysis of the focus group transcripts was conducted. Following the approach used by Vuckovic, Ritenbaugh, Taren, & Tober, ²⁴ transcripts were coded to index categories of responses. The transcripts were independently coded by the investigators and were checked for accuracy against notes taken during the focus groups. ²⁵ The coding process provided a systematic approach to identifying themes in the data. ²⁶ Statements identified from the data were open coded and grouped into conceptual categories, themes or axial codes by consensus among the investigators. ^{26,26-28,28} Themes related to survey questions that were common across both focus groups were identified, as well as themes unique to a particular focus group. The focus group data analysis revealed the following themes. Comments related to each them reflect statements made by unique individuals. Multiple comments by the same individuals are not include as separate statements.

Themes emerging from Focus Group 2 are shown in Table 12. This table shows that these themes include willingness to provide information to help others, the clarity of the language on the survey cover page, the clarity of the language included in Table 1 of the survey, a suggestion to change the language in Table 1 of the survey, lack of clarity regarding the manner in which Table 1 of the survey should be completed, the clarity of language of a number of additional survey items, experiencing symptoms as motivation for previous cancer screening, and overall level of comfort with providing the information requested in the survey.

Themes shown in Table 12 also include the social support and influence factors of preferred ways of learning about cancer screening, urging other focus group participants to get screened for cancer, suggested means of sharing cancer-related information with other African American men and wives as motivators to obtain cancer screening.

Cognitive/psychological factors shown in Table 12 include lack of knowledge regarding cancer, lack of belief in the efficacy of cancer screening tests, the role of African American males' beliefs regarding health and health care, the lack of association between cancer risk behavior and cancer, lack of knowledge of cancer risk factors, knowledge of cancer risk factors, lack of knowledge of cancer symptoms, uncertainty regarding the role of cancer early detection in reducing cancer mortality, seeking knowledge as motivation for previous cancer screening, knowledge of cancer incidence among African American men, lack of belief in the efficacy of cancer screening, belief in the efficacy of cancer screening, belief in the efficacy of cancer early detection, lack of belief in physician efficacy, belief in physician efficacy, fear as a barrier to cancer screening, knowledge of diet as a health risk factor, lack of understanding of the term "flexible sigmoidoscopy", lack of understanding of the term "PSA test" and understanding the role of family history as a cancer risk factor.

Programmatic/systemic factors shown in Table 12 include the suggestion to include screening as part of routine health care, overcrowded clinics, the role of health insurance coverage and the cost of cancer screening, the role of health care providers in cancer surveillance, the gender of physicians in relation to cancer screening and the historic exclusion of African Americans from traditional health care settings.

Table 12. Themes Emerging from Focus Group 2

Theme		Comments Related to the Theme
Willingness to Provide Information to Help Others	0	"The questions and answers that we give, are they going to be used in other surveys or part of the (health) system to make it run smoother?" "I would share anything I have or know to help anybody" "I feel the same way"
Clarity of Language on Survey Cover Page Statement "We are interested in your opinions about your health and the health care that you receive. All of the information that you provide will be kept confidential"	0	"(All) Yes, the statements are clear" "It is the way the sentences are structured. Since you are interested in everybody's opinion on individual health and the individual health care they receive"
Clarity of Language in Table 1	0	"(All) Looks easy to answer" "(It looks easy because of) the way it is structured and the way it is in the boxed and numbered 1-5. It appears to be easy in terms of if you follow the directions, and you can read you should not have a problem completing it. It is laid out pretty self-explanatory"
	0	"Five means stronger, graded in a degree on down I think they (the questions in Table 1) are clear because it is up to the individual to voice your opinion. It's based on you personally"
		"All of them (the questions in Table 1) are clear to me"
	0	"(The survey) asks you the question direct" "I like the way they word this. What we are reading they are not asking you questions, they are looking for you to voice your own opinion Everything in here seems to be simple to me"
Suggestion to Change the Language in Table 1 "(Moderator): Do you think it sounds like there is some question as to whether we are looking for people's opinions or knowledge. Do you think we should say again on this page that we are interested		"(All) "I think so"
in your opinions (and are not testing knowledge)?"		

Theme		Comments Related to the Theme
Lack of Clarity Regarding How to Complete Table 1	0	"The one (answer) that you pick, do you circle it or what?" "These questions, can you just put yes or no?"
Clarity of Language of Questions 13-25	0	"It would be easy to answer these questions" "They are simple questions"
Experiencing Symptoms as Motivation for Previous Cancer Screening		"Didn't want to go (to get screened for cancer). I felt good, didn't want to go It's just like you (another focus group participant) said, 'It's a form of ignorance', just like you said. I should have had a check-up but I didn't"
		"See, that's the whole thing right there. As long as you feel good you figure there is nothing wrong; you're not going there to waste time in the doctor's office"
Overall Level of Comfort with Providing the Information Requested in the Survey	0	"Very comfortable" "Ok"

Theme		Comments Related to the Theme
Social Support and Influence	_	"TV ad"
Factor: Preferred Ways of	0	"I think booklets and pamphlets"
Learning about Cancer Screening		"I think booklets and pamphlets, because other than
		that you might miss it (the information)"
		"Also, if you have ever been there to the clinic there
		in Hospital, you know in the lobby there, one
		time when they were having the screening they had
		the videotapes. Those tapes you know while you are
		sitting there waiting are very informative"
		"I don't think there is enough information about what
	_	would motivate African-American men to get
		checked. That is something that ought to be,
		everywhere you look they ought to be telling you to
		do that, you don't see it"
		"I think what we have to do is get that (cancer)
·	_	information in their face some kind of way. Every
		time they look"
		"Put a pamphlet (with cancer information) behind
		your time card, so when you pick up your time card
		(you will see the cancer information"
	0	"They (African American men) really do need to be
		informed, 'You go and get cured, find out about these
		things because they can be cured'. I am a living
		example of it. I have had all kinds of cancer and I'm
		still here (Having a show on television with cancer
		survivors like the men in this room talking about their
·		experiences who had been diagnosed 10 years ago,
		12 years ago) That would save many lives. That
		would really go far, cancer is not the last word, cure
		is the last word"
		"Some of them (young people) watch those rap
		shows. You can throw it (cancer information) in
		there"
		"(At)Family Center, I guess the older people are
		in there, most of them are retirees. And they go for
		preventive medicine, prescriptions and all kinds of
		stuff. That would be the place to start as far as the
		pamphlets. Ok, you got them all in there; you almost
		got a captive audience because they eat lunch there.
		You know, you take five minutes at lunchtime to say,
		'I have a message for you', before you let them eat.
		Now you've got them captured, now you've got their
		attention, ok and you tell them and you keep stressing
		this (cancer information)"

Theme	 Comments Related to the Theme
Social Support and Influence	"If they (other Black men) had seen the conversation
Factor: Preferred Ways of	we had tonight, you would have these same
Learning about Cancer Screening	conversations in all the work places around the
(cont'd)	country. Tomorrow morning they will be saying,
	'Did you hear what the brother said last night?' Then
	they would start thinking, 'Maybe I need to go do
	that (get screened for cancer).' So this is where it
	needs to be, not in a back room somewhere. It should
	be right out so the public can hear it, us talking
	among ourselves is going no where but back to our
	homes, but if we're in a position where could inform
	them like that I think it would be more helpful"
	"Any way that you could get this (information
	discussed in the focus group, in a similar group
	discussion format) out (to the public via the
	television news media"
	sagreement:
	"Well, that television really doesn't give you too
	much 'cause they are working on time, time means
	everything, and you don't just get it"
	"Young people don't watch television, bunch of
	young people don't watch television, don't read no newspaper"
	"I don't know what media we would use to do that
	(get cancer information to African American men). I
	mean we can't use the TV because we can't afford
	the time. Everybody does not read the paper,
	everybody does not read magazines. You can't get
	all the ministers to talk about it for five minutes in
	church. You got to find a way to get the information
	to them and I don't know how you would do that"
Social Support and Influence	"I tell them all if you haven't been checked for
Factor: Focus Group Participant	prostate cancer, go get checked"
Urged Other Participants to Get	
Screened for Cancer	

Theme	Comments Related to the Theme
Social Support and Influence	"If they (other Black men) had seen the conversation
Factor: Suggested Means of	we had tonight, you would have these same
Sharing Cancer-Related	conversations in all the work places around the
Information with Other African	country. Tomorrow morning they will be saying,
American Men	'Did you hear what the brother said last night?' Then
	they would start thinking, 'Maybe I need to go do
	that (get screened for cancer).' So this is where it
	needs to be, not in a back room somewhere. It should
	be right out so the public can hear it, us talking
	among ourselves is going no where but back to our
	homes, but if we're in a position where could inform
	them like that I think it would be more helpful"
	"Any way that you could get this (information
	discussed in the focus group, in a similar group
	discussion format) out (to the public via the
	television news media"
	"And they (men watching at home) would sit there
	and look at this and they would identify (with the
	men in the discussion) These are people just like
	them"
	"It would help a lot of people"
	"That would save a lot of lives, because they would
	discuss this. I think you gentlemen have some good
	ideas"
Social Support and Influence	"Here is a man that's got insurance he never goes to
Factor: Wife as Motivator to	see the doctor until his wife says ok you are sick go,
Receive Cancer Screening	why doesn't he go on his own, why doesn't say hey
	I'm hurting I'm going to go see the doctor. Nine
	times out of ten, he is not going to do that"

Theme	Comments Related to the Theme
Cognitive/Psychological Factor: Lack of Knowledge Regarding Cancer	"It's (the language in Table 1) fairly simple but how much do you know about cancer? Like "J" for instance, it says, 'Exercising regularly affects your chances of developing cancer'. How do I know if I exercise at all it will affect my chances of getting cancer? I don't have that knowledge I don't know whether exercise help me or not. I know it generally helps you in most areas but I don't know if it would help me in regards to cancer." "I know people who exercise, eat the right foods and still come down with cancer. No smoking, drinking, or a harsh diet and they still got cancer"
Cognitive/Psychological Factor: Lack of Belief in the Efficacy of Cancer Screening Tests	 "All results of cancer screening tests are not accurate. I think it depends on the people who are administering the test and the people that are solving the results of the test" "Too much misdiagnosed. You hear and see it all the time, people going to the doctor and they checked you, they are treating them for arthritis, for this and that, and wind up having bone cancer"
Cognitive/Psychological Factor: Belief in the Efficacy of Cancer Screening Tests	"That's just not the way I was raised. I've been going to the doctor all my life. I go for check-ups. All my kids went. My wife came up in the medical field, so I always believed in going to the doctor, and I encourage all my friends to. I tell them all, go get a check-up, go get this here, they told my wife, how did they find that cancer, she had that cancer call pre-cancer in her lung, because she went to the doctor. Even they told her at Hospital that you never find this kind of cancer this early but that check-up, she and I believe in that, and that is the way we think all the time, that if was not for that she'd be gone, me too" "That's right you'd be gone, too"
Cognitive/Psychological Factor: Role of African American Males' Beliefs Regarding Health and Health Care	"Traditionally, African American men have not gone to doctors. You know a lot of you have worked while you are sick, and you won't go until it is too late or you end up in the hospital by that time it is too late. Why don't you go in for a check-up twice a year? You won't do it"

Theme		Comments Related to the Theme
Cognitive/Psychological Factor: Role of African American Males' Beliefs Regarding Health and Health Care (cont'd)	0 0 0	"He's (African American men are) too macho (to see a doctor). I had Blue Cross all my life but it was 10 or 15 years before I would go and see a doctor but I had the insurance there, but I wouldn't go. And it's a lot of other people that way, too You start feeling bad, that's when I started going (to see a doctor)"
Cognitive/Psychological Factor: Lack of Association Between Cancer Risk Behavior and Cancer		"I smoked for 30 years and never had any cancer"
Cognitive/Psychological Factor: Lack of Knowledge of Cancer Risk Factors	0	"If I don't know that I am at a reduced risk (for cancer) how would I know if I am at a greater risk(for cancer compared to other men)?" "How would I know if compared to other men of my age, how would I know if my risk is far greater? I would almost have to say I have the same risk for the same age. If we are the same age, we have the same risk"
Cognitive/Psychological Factor: Knowledge of Cancer Risk Factors	0	"I think I have reduced risk because I haven't smoked in 50 years, I eat fairly good"
Cognitive/Psychological Factor: Lack of Knowledge of Cancer Risk Factors		"You don't have any symptoms, I didn't have any symptoms. I just stopped by the hospital to get checked and they told me, and that is when they found out I had colon cancer. And there was nothing hurting me then and there is nothing hurting me now I don't know what the signs would be. But I didn't have any symptoms"

Theme		Comments Related to the Theme
Theme Cognitive/Psychological Factor: Lack of Knowledge of Cancer Risk Factors (cont'd)	0	Comments Related to the Theme "I would think that in some cancers, you have no feeling (symptoms) but at other times, there would have to be some type of pain or something that was abnormal" "There is no pain in prostate cancer. I had cancer and had no idea I had it, they operated on me for my bladder and they found out I had prostate cancer" "My doctor kept on telling me that when I get of age I should go on in and have a check-up. So I said, 'Well, I will have the check-up'. When the doctor checked me the next thing he told me is that I got it (prostate cancer). So I went for the operation, but I didn't listen to the doctor, and he kept on telling me that I been walking around not knowing I had it, but I had no warning or anything" "My wife had lung cancer and they removed her lung (and) she didn't know she had cancer I had
Cognitive/Psychological Factor: Uncertainty Regarding the Role of Cancer Early Detection in	0	three different kinds of cancer and I haven't felt anything (any symptoms)" "It says here that cancer if found early it can be cured. Is that true with all cancers?"
Reducing Cancer Mortality Cognitive/Psychological Factor: Seeking Knowledge as Motivation for Previous Cancer Screening	0	"If you have cancer, you have cancer and I want to know (if I have cancer)" "I have been told three times that I have cancer, and each time it's through the roof, you don't want to hear about it, but I am glad I heard it. They (doctors) told me I had six months to live. I didn't want to hear that but I'm glad they told me that so I got me some help, because I don't think that's a hang-up. I think that would be nonsense to not know. I want to know what is wrong with me"
Cognitive/Psychological Factor: Knowledge of Cancer Incidence Among African American Men	0	"Afro-American men, there is a greater incidence of cancer"
Cognitive/Psychological Factor: Lack of Belief in the Efficacy of Cancer Screening	0	"When I had mine (flexible sigmoidoscopy) they didn't find anything and I told them that (they would not) before they went up there" "My biggest fear the fact of going to the doctor and not being diagnosed and going on yearly exams and they don't find it or somehow or another they miss
		it"

Theme		Comments Related to the Theme
Cognitive/Psychological		"I was checked a couple weeks ago. Actually I get
Factor: Belief in the	_	checked every year. So far I haven't been or had
Efficacy of Cancer		cancer"
Screening		
Bereeining		"Same thing here"
	_	"It's worthwhile"
		"Well I have had several of them (flexible
		sigmoidoscopies) but I think they were good and
		worth it because they found some polyps in me that
		were cancerous and some that weren't. So without
:		that they would not have been able to detect it
	_	(cancer)" "It (the flexible signed degrees, procedure) degree?"
		"It (the flexible sigmoidoscopy procedure) doesn't
		miss a thing. After that they told me to come back
0 11 11 11		in three years"
Cognitive/Psychological		"I know my doctor told me that it is not about
Factor: Belief in Efficacy		whether they can cure it. It is about whether they can
of Cancer Early Detection		catch it in time. You've got to catch it in time. That
		is so important"
Cognitive/Psychological		"I think there is a fear there-the fact that when you
Factor: Lack of Belief in		are looking at a person and they are checking you
Physician Efficacy		and they only diagnose certain things or either don't
		tell you every thing that is going on so you get to
		thinking, hey if he wont tell me or she wont tell me,
		I don't care too much for that doctor so you don't go
		to the doctor period unless you are hurting"
Cognitive/Psychological		"We have to trust doctors' technology, we have to
Factor: Belief in Physician		accept that. At least I feel like that. Because you
Efficacy		know, I whole-heartedly accept what doctors tell
		me"
		"I'm going to get a healing for myself or a cure for
		myself and if tell somebody I got the cure then
		maybe they will tell somebody"
		"I was taking 37 treatments here at Hospital.
		Every morning we would have a group like this one
		here, it would be about 50 of us taking these
		treatments. Now a lot of those guys told me if they
		had only known, once that cancer gets into your
		bones they can't cure you. If you inform them and
		they get to these doctors they can be cured"
Cognitive/Psychological		"Most people I talk with seem to be afraid to talk
Factor: Fear as a Barrier to	_	about cancer with you or me"
Cancer Screening		"They don't want to talk about it"
	_	"But most men think it is a shame to have cancer
	_	and they look at you like its got a scorn on you or
		somethingBut don't be afraid to tell somebody
		that you got cancer and you went to get a treatment
		and the doctor said you're cured"
L		

Theme		Comments Related to the Theme
Cognitive/Psychological		"Some people are embarrassed and afraid like
Factor: Fear as a Barrier to		they don't want to talk (about cancer and cancer
Cancer Screening (cont'd)		screening), so that is part of it, too"
		"I want to know also (whether he has cancer) but I
		used to have that fear though, I have had that fear"
		"I fear the cancer; I fear all these other things"
		"No when I was taking my treatments, I was taking
		37 treatments here atHospital. I have cancer
		right now and my doctors tell me I am going to die
		with something else, 'It's not going to be the cancer that kills you'. I don't fear cancer like I used to"
		407 A 1 1 1 1 1 1 A 1 A 1 A 1 A 1 A 1 A 1
		the ones that do fear. And I think that we should get
		help from the professional people like yourself to
		help us. You people have the power to do it, we
		don't. We can tell you our wishes, I would be glad
		to share my experience anywhere"
Cognitive/Psychological		"I think it's our eating habits (that put African
Factor: Knowledge of Diet		American men at risk for health problems)"
as a Health Risk Factor		"When you look at high blood pressure in blacks,
		you eat that greasy food all your life, this is what
		you like, you go in there, they tell you to cut back on
		your salt, cut back on your pork, cut back on your
		eggs, you may do it but how many others will? How
		many others are going to go in there and prescribe
		some medication take that medication everyday to bring it down?"
l		•
Cognitive/Psychological		"I think they (words) are clear, but for me I think
Factor: Lack of	_	you got some words here that are foreign to me"
Understanding of Term		"Question, what is it?"
"Flexible Sigmoidoscopy"		(After hearing description of the flexible sigmoidoscopy) "I have had that procedure done; I
		just didn't know what they call it"
		just druit t know what they can't
Cognitive/Psychological		"I don't know what it is"
Factor: Lack of		"The PSA is not a cancer that is in your blood.
Understanding of Term		When I got my treatments (for prostate cancer) my
"PSA Test"		PSA was 8. Two weeks ago here atHospital it
		was 4, so it is not a cancer that is in your blood"
Cognitive/Psychological		"I think so. I do think it runs in the family"
Factor: Understanding the		"You don't have to get cancer just because someone
Role of Family History as a	_	else in the family got it"
Cancer Risk Factor: "Do		"I do think it runs in the family All my people died of cancer. I had five brothers and all of them
You Think That People Who Have Had Cancer in		died of cancer and my daddy, and I got cancer and I
Their Family Are More		do believe that it runs in the family"
Likely than Other People to	П	"I would agree to that"
Get Cancer?"	_	i mode agree to did
OTT CHILDOI.		

Theme		Comments Related to the Theme
Programmatic/Systemic	0	"When you go in for a regular check-up the doctors
Factor Related to Cancer		check your blood pressure and all those other things
Screening: Need for		that they normally check, why isn't cancer screening
Screening Needs to Be		part of that?"
Included as Part of Routine		"You can't know what they've taken blood tests for,
Health Care		what they are checking for and what they are not
		checking for. You can still have cancer (and not
		know it), is what I am saying"
		"Well you don't know that for sure (doctors check
		for cancer during check-up), because you go there to
		get your check-up They don't tell you all those
		things"
		"They don't tell you what they are checking
		foryou have to ask for it (cancer screening)"
		"You have to ask"
		"They should just automatically do that (check for cancer during routine examination"
		"Some doctors are more thorough than others"
	Di	sagreement:
	D.	"I was in there (the hospital) last month and they
	_	checked for cancer while I was in the hospital"
Programmatic/Systemic		"I would also add that most men middle age and
Factor Related to Cancer		younger black men are short (of) patience. How
Screening: Overcrowded		many times have we all gone into the clinic and the
Clinics		clinic was full and mostly what you saw in the clinic
		was women and kids and the men were there, they
		were out in the car waiting because they brought
		them (the women and children) up there (to the
		clinic). You did not see them sitting in there waiting
		to see the doctor"
Programmatic/Systemic		"I was also told that it (flexible sigmoidoscopy) was
Factor Related to Cancer		a very costly type of exam and the insurances do not
Screening: Health		allow you to go in routinely to take this type of
Insurance Coverage and the		exam"
Cost of Cancer Screening		"I saw something on TV about the insurance, how
		much they pay and how much the cost of the test,
	_	too much is misdiagnosed" "Samah day made to take a leak at the rough matient
		"Somebody needs to take a look at thorough patient
		care. I don't care how much money is involved.
		Somebody is always talking about how the HMO
		will only pay this amount. They need to stop
		playing with people's lives because of money. They
		diagnosed this lady three different times before they
		finally said it was cancer but it was too late she was
		too far-gone. That is what is scary, not the cancer"

Theme		Comments Related to the Theme
Programmatic/Systemic		"If they have to check all those things (screens for
Factor Related to Cancer		cancer), that will take more time and more lab work
Screening: Health		and that is where all that money comes in. People
Insurance Coverage and the		may not want to believe but a lot of it weighs on
Cost of Cancer Screening		that. Its bad to say but it is true"
(cont'd)		
		"I think that there are a lot of black individuals that
		don't come in for an exam period, so therefore you
		have to be able to get to them and then a lot of
		them don't have health insurance"
		"We (black people) have not had the good insurance
	_	(that facilitate cancer screening)"
		"We have a lot of homeless here in the city that are
		not getting any kind of care, and so therefore with a
		shortage of facilities and no health care and then they are in and out of these rescue missions, you
		know, being fed. They are getting a meal, put
		together by these rescue missions in the
		neighborhoods but there again they are not getting
		any type of health care"
Programmatic/Systemic		"I have an appointment tomorrow for a check-up,
Factor Related to Cancer	_	because they check me every 90-days now; every 90
Surveillance: Role of		days to see how my cancer is doing - leukemia"
Health Care Providers in		
Cancer Surveillance		
Programmatic/Systemic	_	"I have had a female doctor for so long the
Factor: Gender of	_	female doctor I have, they do not check as a man
Physicians As Related to		would check a man. So at the time I got my prostate
Cancer Screening		checked in the past five years was through the
		screening (outside of his health care location), so the
		only thing that is going on in my mind now is if they
		stop that free screening, do I have to find me another
		male doctor or go back to the clinic where I was
		going before see a male doctor to get a check-up? A
		lot of time they (female doctors) don't check you.
		They will come in and say, 'Well, how are you
		doing?' and ask if anything is bothering you." And
		they will go as far as they are going to go being a
		female with a male patient. I'm not saying women
		are not good doctors, I'm just saying that they don't
		catch it when I do come for the physical"

Theme		Comments Related to the Theme
Programmatic/Systemic Factor: Gender of Physicians As Related to Cancer Screening (cont'd)		"I had a female check my prostate and I would rather have a man. Those females are rough It does not make a difference, but I'm just telling you which ones are rough" "I would rather see a male (doctor)"
Programmatic/Systemic Factor: Historic Exclusion of African Americans from Traditional Health Care Settings		"A whole lot of these things (health issues) we are suffering now come from our heritage. You have to look at things the way they really are. Our heritage dictates a lot of these things. A lot of these things we don't know to do (such as make adequate use of health services), and it comes from the way society has pushed us in a corner. I don't call it equal I am afraid of that word, it is kind of what you have been forced to accept Why don't you have the money (to pay for health care)? Because you were ostracized and didn't have a chance to get it"
		"And what was available to you"
	0	"A lot of things come from the lack of money"

KEY RESEARCH ACCOMPLISHMENTS

- An abstract describing the focus group results was submitted for presentation at the 2001 Annual Meeting of the Gerontological Society of America.
- An abstract documenting the design of the funded research was submitted for presentation at the 2000 meeting of the American Association for Cancer Research.
- Two focus groups assessing the perceptions of older African American men toward cancer screening were conducted.
- A manuscript describing the focus group results is being prepared and will be submitted by December 2001 to a peer-reviewed journal for publication consideration. An outline of the manuscript describing the focus group results has been completed. The outline is as follows:
 - A. Description of two themes:
 - 1. Development of a culturally appropriate instrument designed to assess perceptions of cancer screening among African American men
 - 2. Perceptions of cancer and cancer screening elicited from the focus group participants
- B. Impact of the PLCO cancers on African American men
- C. Relationship between perceptions of cancer and cancer screening and participation in cancer screening among African American men
- D. Relationship between these perceptions and the development of culturally appropriate screening interventions designed to address these perceptions
- E. Description of the process of developing the culturally appropriate instrument

- 1. Literature review to develop content areas for the instrument
- 2. Focus Group 1 designed to ascertain the validity of the content areas of the instrument for African American men
- 3. Revision of the instrument based on the focus group results
- 4. Focus Group 2 designed to ascertain the validity of the terms and format used in the instrument for African American men
- F. Themes emerging from Focus Group 1
- G. Themes emerging from Focus Group 2
- H. Implications of the focus group results for the development of cancer screening interventions for African American men
- A manuscript describing the case management approach is being prepared and will be submitted by December 2001 to a peer-reviewed journal for publication consideration. An outline of the manuscript describing the case management approach has been completed. The manuscript will be submitted in November 2001 for publication consideration to the peer-reviewed journal, *Health and Social Work*. The manuscript outline is as follows:
 - A. Impact of the PLCO cancers on African American men
 - B. Description of the DOD Phase I case management intervention
 - C. Case studies 1 and 2
 - D. Implications of the findings for
 - 1. Developers of clinical trials
 - 2. The role of social workers in facilitating health services utilization among African American men

E. Conclusions

- A presentation describing the case management approach is being prepared and will be presented in September 2001 to the Director of the Josephine Ford Cancer Center and to the Director of Epidemiologic Research at the Josephine Ford Cancer Center, Henry Ford Health Sciences Center. The presentation is the basis of the manuscript describing the case management approach.
- Because of the nature of this study, Dr. Ford was invited to participate in the National Institutes of Health/National Cancer Institute, Division of Cancer Control and Population Sciences Workshop on Behavioral Intervention Research and Assessment for Colorectal Cancer Screening. This meeting took place December 9-10, 1999 in Washington, D.C. The purpose of the meeting was to assess the status of behavioral research related to colorectal cancer screening.
- Dr. Ford was invited to participate in the National Institutes of Health/National Cancer Institute's Colorectal Cancer Progress Review Group Roundtable. The goal of the Roundtable, which took place January 5-7, 2000, in Washington, D.C., was to establish a national research agenda for colorectal cancer.
- Dr. Ford was invited in 2000 to become a member of Member of the National Institutes of Health Risk, Prevention & Health Behavior IRG - Study Section 3. This National Institutes of Health Behavioral Health study section group meets three times per year to review proposals written by scientific peers.
 - A questionnaire has been developed that will assess perceptions of African American men toward cancer screening. The concepts in this questionnaire are being modeled after the concepts in the Preventive Health Model.⁵ In a future study, the factor

structure of the newly developed questionnaire will be compared with the theoretical framework found in the Preventive Health Model.⁵

REPORTABLE OUTCOMES

Manuscripts, abstracts, presentations:

The following abstract was submitted in April 2001 for presentation consideration at the 2001 Annual Meeting of the Gerontological Society of America.

Developing A Survey To Assess Cancer Screening Perceptions Of Older African American Men. Jankowski M, Ford ME, Parrish L, Butler A, Vernon S, Swanson GM. Henry Ford Health System, RCMAR, 1 Ford Place, 3E, Detroit, MI 48202. African American (AA) men have higher cancer incidence and mortality rates than Caucasian (C) men. Cancer screening perceptions influence screening behavior and early detection. The goals of this study were: (1) to validate, through focus groups, a survey assessing cancer screening perceptions of older AA men and (2) to describe the perceptions of focus group members. Survey items, derived from a literature review, were grouped into the cognitive/psychological (C/P) factors, social support and influence (SSI) factors and programmatic/systemic (P/S) factors of the Preventive Health Model. For each focus group, AA male patients aged 55+ years were randomly selected. Focus group #1 was held with 10 men ranging in age from 55-87 years, with a mean age of 73.4 years. The 11 men in focus group #2 had an age range of 53-81 years, with a mean age of 68.7 years. The survey items and wording were validated in the focus groups. During the focus groups, C/P factors of fear and anxiety regarding cancer diagnosis and lack of knowledge about screening tests and screening benefits were stated. Wives were noted as the most important SSI persons affecting screening behavior. Having a trusted health care provider and health insurance were cited as P/S screening-related factors.

An abstract describing the retention study was submitted on November 1, 1999 for consideration as a presentation at the American Association of Cancer Research Conference in April 2000. The abstract is described in the following paragraphs.

Retaining African American Men in a Cancer Screening Trial: Challenges, Solutions, and Focus Group Results. Ford ME, Swanson GM, Vernon S, Hill D, Jankowski M, Randolph V, Johnson CC. Resource Center for Minority Aging Research and Josephine Ford Cancer Center, Henry Ford Health System, Detroit, MI 48202

This presentation describes challenges faced in carrying out a retention study involving African American men and solutions to these challenges. The objective of the retention study, begun in July 1999, is to identify innovative methods for increasing the retention of African American men in prostate cancer screening trials. Retention, while important for all groups, is especially critical for African American men, given their often low representation in clinical trials. The specific aims are to evaluate the efficacy of an

intervention designed to retain African American men in the screening arm of the Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial at the Henry Ford Health System site, and to develop a culturally appropriate measurement instrument to assess perceptions of screening for these cancers among older African American men. The study population consists of African American men aged 55 and older living in the Detroit area. Blocked randomization methods were used to assign the men to the retention intervention or control group. A retention coordinator provides intense follow-up to the men in the intervention group and guides them through the PLCO Trial cancer screening processes. It is hypothesized that men in the intervention group will show higher screening adherence rates than men in the control group. An instrument to assess cancer screening perceptions among older African American men will be developed using focus group techniques. The results of these focus groups are described in the presentation.

CONCLUSIONS

Issues related to the implementation of the behavioral intervention and other aspects of the study protocol

The behavioral intervention has been designed to overcome barriers to continued trial participation. The main element of the intervention is a retention coordinator, who establishes and maintains monthly telephone-based contact with PLCO Trial participants in the intervention arm of the study, and who serves as a source of information about relevant health and social services. This intervention is based upon the systems approach in the field of social work, in which a case manager serves as a link between clients and needed resources and resource systems by serving as a source of information about these resources and systems. While somewhat more limited in breadth than a traditional case manager, the retention coordinator nonetheless attempts to maintain a similar depth of personal relationships with the PLCO Trial participants as a case manager would with her or his clients.

Four barriers to the participation of minority populations in clinical trials have been identified by Swanson and Ward.²⁹ These are sociocultural barriers, economic barriers, individual barriers, and barriers inherent in study design, which can affect not only recruitment to cancer screening trials but also continued participation in these trials as well. The innovative telephone-based retention strategy administered by a retention coordinator has been designed to address these barriers to continued trial participation. Sociocultural Barriers - These barriers include fear and mistrust of federally sponsored projects. In the present study, the retention coordinator, a person of the same race as the study participants, aims to develop rapport with the participants and build a sense of trust with them. The retention coordinator provides participants and their spouses/partners with requested information pertaining to the PLCO Trial as well as other questions they have related to health and social services. Economic Barriers - These barriers are addressed in the proposed recruitment study. The retention coordinator serves as a clearinghouse for information related to older adults and their families, such as that provided by local Area Agencies on Aging and local senior centers. Addressing issues of

importance to participants may help to free them from some economic worries, thus allowing them to focus on their cancer trial participation. Individual Barriers - Individual barriers include denial and underestimation of personal vulnerability. It is hoped that the customized approach of the telephone calls from the retention coordinator will reduce individual barriers to participation as well as sociocultural barriers, as health issues pertinent to older African American men are addressed during these telephone conversations. Barriers Inherent in Study Design - The proposed study is designed to minimize barriers inherent in study design, which Swanson and Ward²⁹point out can significantly reduce study participation rates. The retention coordinator guides the men assigned to the intervention arm of the study through the PLCO Trial screening processes.

Challenges and Solutions

- (a) Originally, the retention coordinator was only going to contact men assigned to the intervention arm of the present study. Existing PLCO Trial schedulers would make screening appointments for men assigned to the control arm of the study. However, one of the co-investigators pointed out the fact that this could serve to introduce bias into the study. The study protocol has been changed so that the retention coordinator now makes all of the contacts with the all of the men in the study. This protocol change will help to reduce bias that might be associated with style differences in interacting with the study participants. The retention coordinator contacts the men in the intervention arm (n=301) by telephone on a monthly basis and also schedules yearly PLCO Trial cancer screening appointments for the men in the control arm (n=300) of the study.
- (b) During the first two months of the study, the retention coordinator was not able to speak via telephone with 35 men because they were not available when she called. After some discussion, the research team made the decision that the retention coordinator would leave messages on the answering services of the men. In the message, the retention coordinator introduces herself as a resource person for the men, and lets them know that she is will call them on a monthly basis, and that she is available to help them to find answers to questions they or their family may have. At the end of the message, the retention coordinator leaves her telephone number, and asks the participant to call her. The retention coordinator now leaves similar messages with all men she is not able to speak with directly when making the monthly calls, although she continues to call them throughout each month in an attempt to speak directly with them.
- (c) In order to maximize the number of intervention group participants with whom the Retention Coordinator speaks directly each month, the process of mailing requested information has been delegated to a staff secretary. We did not expect study participants to ask for as great an amount of information as they are currently requesting. Information is being requested related to transportation, food services, recipes, medication, various diseases, literacy, housing, social security, and child care. For example, the retention coordinator has been asked by the spouses of study participants for information related to the participant's grandchildren. Because of the volume of information requested, the responsibility of mailing information to participants has been given to a staff secretary. The secretary now generates the cover letters accompanying the mailed materials. The

Retention Coordinator then signs the cover letters, and the completed information packets are then mailed by the secretary. During the planning stage of the study, the retention coordinator contacted a number of local agencies to receive information related to the services provided by these agencies. A file was developed listing the agencies and the services provided. This file serves as a source for locating information requested by study participants. Other sources of information include the Internet, the Yellow Pages, radio and television announcements, agency newsletters, and a directory of local human services. A listing of community resources used in the study is included in Appendix C.

- (d) In a previous study involving recruitment of African American men to the PLCO Cancer Screening Trial, it was discovered that the men's female spouses/partners served as gatekeepers. If the women did not think their spouses/partners should participate in the PLCO Trial, the women would not give the telephone to them during the recruitment calls. Therefore, in the retention study, the intervention was designed to include female spouses/partners in order to garner their support for the project, and to potentially serve to help retain the men in the study. For example, during each telephone call, the retention coordinator asks to speak with the participant's spouse/partner, if he has one. If the retention coordinator than introduces herself and asks if they would like information related to particular topics. If the retention coordinator has spoken previously with the spouse/partner, the retention coordinator follows up on previous conversations, and gives the spouse/partner information they requested.
- (e) The retention coordinator maintains computerized files detailing which men have been contacted each month. During the third month of the study, the retention coordinator noted that it would be helpful not only to know which men were called, and which still needed to be called each month but also the time of day and day of the week when the men were reached. The retention coordinator felt that this additional information would assist her in successive months to contact the men during a time when they could be reached. Subsequently, information related to the time of day and day of the week each participant was reached was added to the computerized files.

In summary, the findings of this study can be used to help African American men benefit from the positive aspects of participation in prostate cancer research. The focus group findings will lay the foundation for a future study designed to assess differences in perceptions of cancer screening among African American men of different ages, and to identify potential drop-outs, who could then receive the intensive follow-up provided by a retention coordinator. The study has gone well to date. A number of challenges have been encountered and solutions to these challenges have been proposed.

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APPENDIX A

"African American Men in the PLCO Trial: Developing And Testing Methods To Increase Retention"

Consultant Meeting Agenda

May 24-25, 1999

May 24, 1999 (Room 3C08, 8:30 a.m. – 5:00 p.m.)

- I. Introductions
- II. Overview of the Department of Defense-funded study "African American Men In The PLCO Trial: Developing And Testing Methods To Increase Retention"
- III. Study Update
- IV. Description of Remaining Work
- V. Review of the Study Timeline
- VI. Development of Focus Group Questions Assessing Attitudes of African American Men Toward Cancer Screening (Review of Similar Work Conducted at Henry Ford Health System with African American Women to Ascertain the Cultural Appropriateness of A Breast Cancer Risk Factor Survey)

May 25, 1999 (Room 1C00, 8:30 a.m. – 2:30 p.m.)

Development of Focus Group Questions (continued)

APPENDIX B

SCRIPT FOR ATO MALE

INTRODUCTORY TELEPHONE CALL

Hello, is this Mr.	? My name is	. As part of a
research project to help Prostate, Lung	, Colorectal and Ovari	an (PLCO) Cancer
Screening Trial participants receive their ca	ncer screenings, I have be	en assigned to assist
you in receiving your screenings. I would	like to call you on a mon	thly basis to serve as
a resource person, to help to find answers	to your questions about t	hings such as Social
Security, Medicare, health issues or other	er concerns. I could ev	en assist you with
questions concerning your friends, children,	and grandchildren.	, , , , , , , , , , , , , , , , , , , ,

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.
Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.
If SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR ATO MALE

FIRST MONTH

Hello, is this Mr.	? My name is	. How are
Hello, is this Mr	(PLCO) Cancer Screen	ing Trial participants
person, to help to find answers to your que Medicare, or other health issues. I could exfriends, children, and grandchildren.	estions about things suc	ch as Social Security.
Some of the people I've talked to recently he the health of their family members and friend	ave mentioned concerns	about their health or
transportation, chore services for seniors, ch family members, finances and financial assi depression, anger, religion, substance abuse	aild care, education of the stance, food/nutrition, he	emselves or their
Are any of these things (or other things) a co	oncern for you?	
WRITE DOWN THE THINGS THE INFORMATION IN OUR FILES TO HE THEM ON THE TELEPHONE. GIVE THE NUMBER(S). STATE:	ELP THE PERSON W	WHILE YOU HAVE
Mr, you mentioned I would like to give you the agence	cy's telephone number so	that you can call for
more information. Do you have a pen? If WE HAVE AN IDENTIFIED CONTACT Applease ask for Mr./Ms	Here is the telephone num AT THE AGENCY, STA	mber: IF ATE: When you call,
Do you have any other concerns you would l	like to discuss today? (P	ROBE AGAIN FOR
SPECIFIC CONCERNS. WRITE THE TELEPHONE NUMBER OF SOMEONE	M DOWN AND TR' WHO CAN HELP TO	Y TO FIND THE ADDRESS THOSE

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

lives of their children, family or friends. I will call again next month. IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called. IF SPOUSE/PARTNER IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is ____. How are you? When we talked recently. I let you know that, as part of a research project to help Prostate. Lung. Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes. transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid. depression, anger, religion, substance abuse, transportation, etc. Are any of these things (or other things) a concern for you? WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: Ms. _____, you mentioned _____. There is an agency, , that helps to . I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: . IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms. . . Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS). IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms. ____, let me check my files to find some information about . Here it is. There is an agency, , that helps to . I would like to give you the agency's telephone number so that you can call for

about any questions or concerns they may have about something in their own lives or the

more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR ATO MALE

SECOND MONTH

Hello, is this Mr.	? My na	me is	. How are
you? When we talked recently, I let you	know that, as pa	art of a research proj	ect to help
Prostate, Lung, Colorectal and Ovariar			
receive their cancer screenings, I will cal			
person, to help to find answers to your			
Medicare, or other health issues. I could	even assist you	with questions conce	rning your
friends, children, and grandchildren.			
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TART OF SCRIFT.			
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ADDRESS THEIR CONCERNS, STAT			
answered/your concerns were not address	sed. I would like	to assist you in fin	ding some
auswers. While I have you on the telepho	one, I will check:	my files again to see	whether I
have more information on this topic.			
IF VOIT DON'T HAVE AND MODE IN	EODMATION O	N THE TONG OT	ATC. M.
IF YOU DON'T HAVE ANY MORE IN, I will call you back later with ac	rokwalion o	in Iriis Turic, Si.	AIE: Mr.
we talked last month, you also mentioned	that you were a	ion. Before we nang	g up, when
you able to find the information you were			
TO FIND THE INFORMATION, STA			
questions answered/your concerns address	sed. GO TO NEX	CT PART OF SCRIP	T
,		0. 00.00	••
IF PARTICIPANT WAS NOT ABLE T	O FIND THE IN	FORMATION NE	EDED TO
ADDRESS THEIR CONCERNS, STAT	E: I am sorry	that your questions	were not
answered/your concerns were not addre	ssed. IF YOU I	DON'T HAVE AN	Y MORE
INFORMATION ON THIS TOPIC, STA		, I will call you	back later
with additional information			

Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
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Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

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SCRIPT FOR ATO MALE

THIRD MONTH

Hello, is this Mr	? My name is	How are
you? When we talked recently, I let you know Prostate, Lung, Colorectal and Ovarian (Proceive their cancer screenings, I will call you	LCO) Cancer Screening Tr	rial participants
person, to help to find answers to your ques Medicare, or other health issues. I could eve friends, children, and grandchildren.	stions about things such as	Social Security,
Mr, when we talked last month, you were you able to find the in PARTICIPANT WAS ABLE TO FIND THE were able to have your questions answered PART OF SCRIPT.	nformation you were lool E INFORMATION, STATE	king for? IF : I'm glad you
IF PARTICIPANT WAS NOT ABLE TO F ADDRESS THEIR CONCERNS, STATE: answered/your concerns were not addressed. answers. While I have you on the telephone, have more information on this topic.	I am sorry that your quest I would like to assist you i	stions were not in finding some
IF YOU DON'T HAVE ANY MORE INFOR- , I will call you back later with addition we talked last month, you also mentioned that you able to find the information you were loc TO FIND THE INFORMATION, STATE: questions answered/your concerns addressed.	onal information. Before we t you were concerned about oking for? IF PARTICIPAN I'm glad you were able	hang up, when Were IT WAS ABLE to have your
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Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
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ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today. Mr. ____ If you have any questions, please write them.

nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

IF SPOUSE/PARTNER IS NOT AVAILABLE. STATE: Please let them know that I called. IF SPOUSE/PARTNER IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is . How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings. I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security. Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. , when we talked last month, you mentioned that you were concerned about . Were you able to find the information IF SPOUSE/PARTNER WAS ABLE TO FIND THE you were looking for? I'm glad you were able to have your questions INFORMATION, STATE: answered/vour concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. , I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

about any questions or concerns they may have about something in their own lives or the

lives of their children, family or friends. I will call again next month.

Are any of these things (or other things) a concern for you?

INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR ATO MALE

ANNUAL SCHEDULING CALL

Hello, is this Mr.	? My name is	How are
you? When we talked recently, I let you k	cnow that, as part of a research	ch project to help
Prostate, Lung, Colorectal and Ovarian	(PLCO) Cancer Screening	Trial participant
receive their cancer screenings, I will call	you on a monthly basis to se	erve as a resource
person, to help to find answers to your qu		
Medicare, or other health issues. I could e	even assist you with questions	s concerning you
friends, children, and grandchildren.		
Mr, you have been selected to be		
cancer screening exams. I would like t	o schedule an appointment	so you can take
advantage of them.		

With this being your first year in the study, your exams will consist of:

- A blood test
- Chest x-ray
- An exam of the prostate
- And a flexible sigmoidoscopy

Since there is preparation involved for your exams, we will send you a packet containing two Fleet enemas and the instructions, a map to the location, and a letter confirming the day, date, time, and location of your appointment.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which of these would be closest to you?
(AFTER DETERMINING THE NEAREST CLINIC)

Because all of the exams are done in the one visit, it will take approximately an hour and a half to two hours for your appointment. Are mornings or afternoons best for you?

Are you available on (day), (date) at (time) at (clinic)?

(AFTER SCHEDULING THE APPOINTMENT), We will be sending you a letter confirming the day, date, and time of your appointment.

I have your address as (address), (street name), (city), (zip code). Is this correct?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM I HROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, since this is your first time getting these screenings, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.
IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
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Are any of these things (or other things) a concern for you?

And any of these amigs (or other mangs) a consecutive year
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ASK: Mr, did you have any other questions or concerns about something in your own life or the lives of your family or friends?
IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.
? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung. Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource
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Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR A TO MALE

ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr.	? My name is	s	I'm calling
from the PLCO study at Henry Ford Hospital.	You have bee	n selected to be	in the group
of the study that will receive free cancer scree	ening exams.	I would like to	schedule an
appointment so you can take advantage of them	ı.		oute and

With this being your first year in the study, your exams will consist of:

- A blood test
- Chest x-ray
- An exam of the prostate
- And a flexible sigmoidoscopy

Since there is preparation involved for your exams, we will send you a packet containing two Fleet enemas and the instructions, a map to the location, and a letter confirming the day, date, time, and location of your appointment.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which of these would be closest to you?

(AFTER DETERMINING THE NEAREST CLINIC)

Because all of the exams are done in the one visit, it will take approximately an hour and a half to two hours for your appointment. Are mornings or afternoons best for you?

Are you available on (day), (date) at (time) at (clinic)?

(AFTER SCHEDULING THE APPOINTMENT), We will be sending you a letter confirming the day, date, and time of your appointment.

I have your address as (address), (street name), (city), (zip code). Is this correct?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, a flexible sigmoidoscopy, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, since this is your first time getting these screenings, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. _____, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.
If SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.
All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T1 MALE

INTRODUCTORY TELEPHONE CALL

Hello, is this Mr.	? My name is	As part of a
research project to help Prostate, Lung,	Colorectal and Ovarian	(PLCO) Cancer
Screening Trial participants receive their can	cer screenings, I have been	assigned to assist
you in receiving your screenings. I would li	ke to call you on a monthly	basis to serve as
a resource person, to help to find answers to	your questions about thing	gs such as Social
Security, Medicare, health issues or other	concerns. I could even	assist you with
questions concerning your friends, children,	and grandchildren.	

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

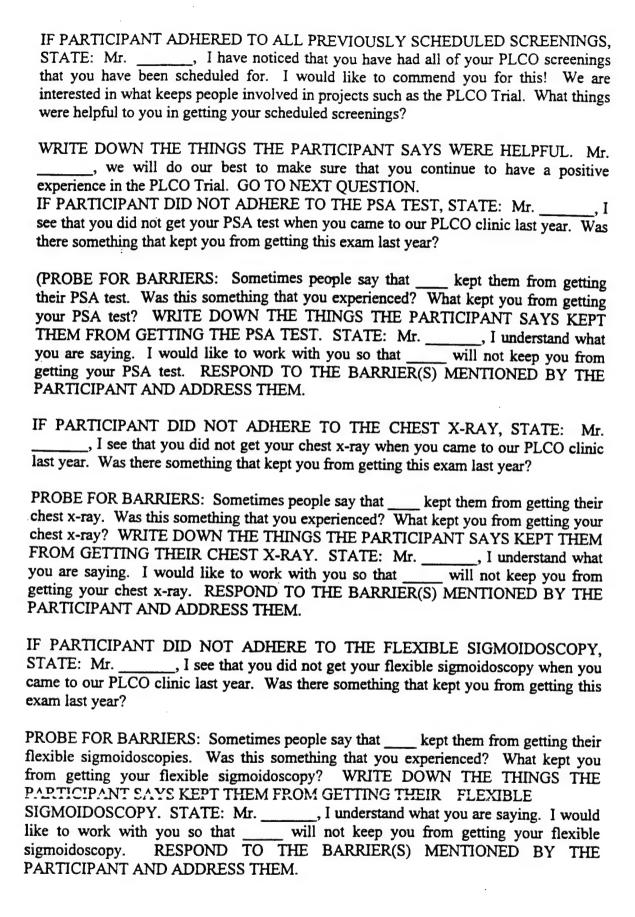
Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.
Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.
IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.
All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T1 MALE

FIRST MONTH

Hello, is this Mr? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.
Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.
Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Mr, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).



IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM, STATE: Mr, I see that you did not get your digital rectal exam when you came to our PLCO clinic last year. Was there something that kept you from getting this exam last year?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS, STATE: Mr, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings last year? (PROBE FOR BARRIERS.)
Mr, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

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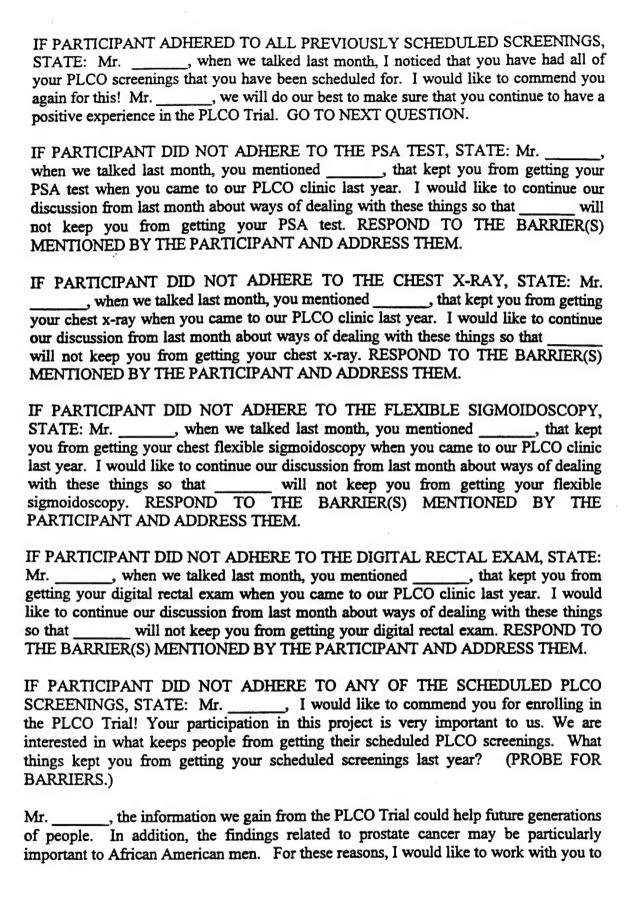
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SCRIPT FOR AT1 MALE

SECOND MONTH

Hello, is this Mr	n (PLCO) Cancer Screenin all you on a monthly basis to questions about things such	g Trial participants serve as a resource as Social Security,
Mr, when we talked last month Were you able to find to PARTICIPANT WAS ABLE TO FIND were able to have your questions answ PART OF SCRIPT.	he information you were THE INFORMATION, STA	looking for? IF ATE: I'm glad you
IF PARTICIPANT WAS NOT ABLE TAIL ADDRESS THEIR CONCERNS, STATE answered/your concerns were not address answers. While I have you on the telephoave more information on this topic.	TE: I am sorry that your sed. I would like to assist y	questions were not you in finding some
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Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancerfree prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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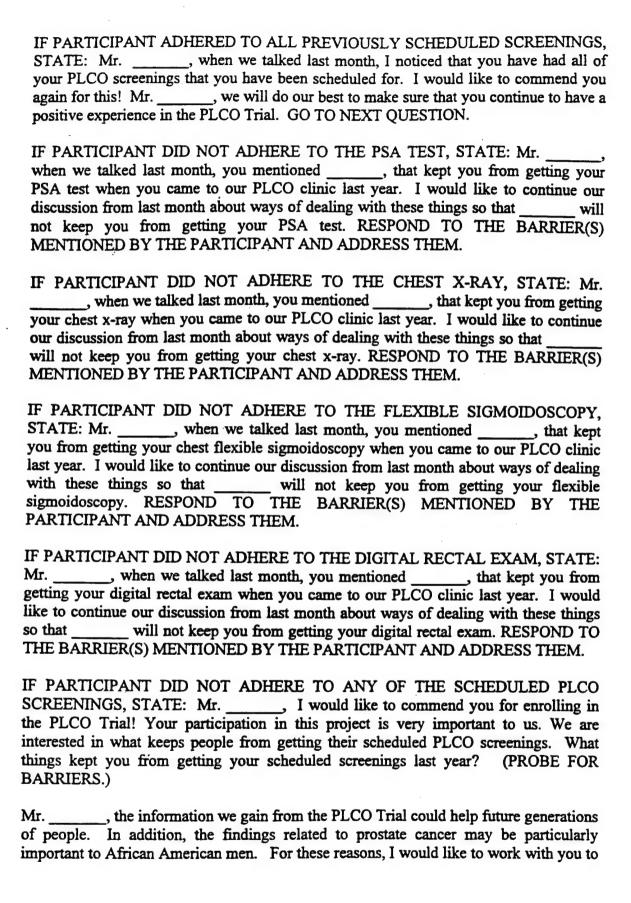
SCRIPT FOR AT1 MALE

THIRD MONTH

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SCRIPT FOR AT1 MALE

ANNUAL SCHEDULING CALL

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person, to help to find answers to you	ur questions about things such a	as Social Security,
Medicare, or other health issues. I cou	ıld even assist you with questior	as concerning your
friends, children, and grandchildren.		
Mr, I would like to schedule	you for this year's free cancer so	reening exams.
First, have you been diagnosed with car		
IF NO, CONTINUE. IF YES, CONT	TINUE BUT DO NOT OFFER	OR SCHEDULE
AN EVAMOE THAT DICO ODGANI		

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as <u>(read from the overview)</u>. Is that correct? And is your physician Dr. <u>(from the overview)</u> at <u>(address and city)</u>?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

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ASK: Mr, did you have any other questions or concerns about something in your own life or the lives of your family or friends?
IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.
IF SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, is this Ms. ? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms, when we talked last month, you mentioned that you were concerned about Were you able to find the information

you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms.
______, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about ______. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR A T1 MALE

ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr.	? My name is	I'm calling
from the PLCO study at Henry Ford Hospital.	I would like to sche	dule this year's free
cancer screening exams.		

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum? IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as <u>(read from the overview)</u>. Is that correct? And is your physician Dr. <u>(from the overview)</u> at <u>(address and city)</u>?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. _____, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
IF SPOUSE/PARTNER IS NOT AVAILABLE, STATE: Please let them know that I called.
If SPOUSE/PARTNER IS AVAILABLE, STATE: Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.
All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T2 MALE

INTRODUCTORY TELEPHONE CALL

Hello, is this Mr.	? My name is	As part of a
research project to help Prostate, Lung,	Colorectal and Ovarian	(PLCO) Cancer
Screening Trial participants receive their can	cer screenings, I have been	assigned to assist
you in receiving your screenings. I would li	ke to call you on a monthly	basis to serve as
a resource person, to help to find answers to	your questions about thin	gs such as Social
Security, Medicare, health issues or other	-	_
questions concerning your friends, children,		,

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit:
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.
Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T2 MALE

FIRST MONTH

Hello, is this Mr. you? When we talked recently, I let Prostate, Lung, Colorectal and Overeceive their cancer screenings, I will person, to help to find answers to y Medicare, or other health issues. I confriends, children, and grandchildren.	you know that, as part of a resear arian (PLCO) Cancer Screening Il call you on a monthly basis to so your questions about things such a	rch project to help Trial participants serve as a resource as Social Security
Some of the people I've talked to receive the health of their family members and transportation, chore services for senifamily members, finances and finance depression, anger, religion, substance	nd friends, the health care they receiors, child care, education of thems ial assistance, food/nutrition, housi	eive, safety, taxes, selves or their
Are any of these things (or other thing	gs) a concern for you?	
WRITE DOWN THE THINGS INFORMATION IN OUR FILES THEM ON THE TELEPHONE. GIV NUMBER(S). STATE:	TO HELP THE PERSON WHI	LE YOU HAVE
Mr, you mentioned I would like to give you the more information. Do you have a per WE HAVE AN IDENTIFIED CONT please ask for Mr./Ms	e agency's telephone number so the en? Here is the telephone number ACT AT THE AGENCY, STATE	at you can call for er: IF
Do you have any other concerns you verified the second of	THEM DOWN AND TRY	TO FIND THE

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS STATE: Mr, I have noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What things were helpful to you in getting your scheduled screenings?
WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your PSA test when you came to our PLCO clinic • last year • two years ago • last year and two years ago.
Was there something that kept you from getting this exam last year two years ago last year and two years ago?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your chest x-ray when you came to our PLCO clinic • last year • two years ago • last year and two years ago.
Was there something that kept you from getting this exam last year two years ago last year and two years ago?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr, I understand what

getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. , I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic
 two years ago. Was there something that kept you from getting this exam two years ago?
two years ago:
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE-DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your digital rectal exam when you came to our PLCO clinic last year two years ago last year and two years ago.
Was there something that kept you from getting this exam last year two years ago last year and two years ago?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps

people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

- last year
- two years ago
- last year and two years ago?

(PROBE FOR BARRIERS.)

Mr. _____, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is . How are you? When we
? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.
Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.
Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have vou on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call,
please ask for Mr./Ms

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. _____. If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT2 MALE

SECOND MONTH

Hello, is this Mr.	? My name is	. How ar
you? When we talked recently, I let yo Prostate, Lung, Colorectal and Ovaria	u know that, as part of a resea	rch project to help
receive their cancer screenings, I will cancer screenings, I will cancer screenings.	all you on a monthly basis to s	serve as a resource
person, to help to find answers to your	questions about things such a	as Social Security
Medicare, or other health issues. I coul	d even assist you with question	as concerning you
friends, children, and grandchildren.		
Mr, when we talked last monto were you able to find to PARTICIPANT WAS ABLE TO FIND were able to have your questions answ PART OF SCRIPT.	the information you were led THE INFORMATION, STATE	ooking for? IF TE: I'm glad you
IF PARTICIPANT WAS NOT ABLE ADDRESS THEIR CONCERNS, STA answered/your concerns were not address answers. While I have you on the telephhave more information on this topic.	TE: I am sorry that your quessed. I would like to assist you	uestions were not
IF YOU DON'T HAVE ANY MORE IN, I will call you back later with a	NFORMATION ON THIS TOP	PIC, STATE: Mr.
we talked last month, you also mentione	d that you were concerned abo	out . Were
you able to find the information you wen	re looking for? IF PARTICIPA	ANT WAS ABLE
TO FIND THE INFORMATION, STA questions answered/your concerns addres	ATE: I'm glad you were al	ble to have your
IF PARTICIPANT WAS NOT ABLE 1	O FIND THE INFORMATIC	N NEFDED TO
ADDRESS THEIR CONCERNS, STA	TE: I am sorry that your qu	estions were not
answered/your concerns were not addr	essed. IF YOU DON'T HAY	VE ANY MORE
NFORMATION ON THIS TOPIC, ST with additional information.	ATE: Mr, I will ca	ill you back later

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Mr, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your PSA test when you came to our PLCO clinic • last year • two years ago • last year and two years ago.
I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest x-ray when you came to our PLCO clinic • last year • two years ago
 last year and two years ago.
I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic • two years ago.
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IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your digital rectal exam when you came to our PLCO clinic

- last year
- · two years ago
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IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. _____, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned _____, that kept you from getting your PLCO screenings when you came to our PLCO clinic

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Mr. _____, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

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ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

lives of their children, family or friends. I will call again next month. SPOUSE IS AVAILABLE TO TALK. STATE: Hello, is this Ms. IF ? My name is . How are you? When we talked recently. I let you know that, as part of a research project to help Prostate, Lung. Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security. Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. , when we talked last month, you mentioned that you were concerned about . Were you able to find the information IF SPOUSE/PARTNER WAS ABLE TO FIND THE you were looking for? INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. , I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

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WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND

Are any of these things (or other things) a concern for you?

INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
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SCRIPT FOR AT2 MALE

THIRD MONTH

Hello, is this Mr.	? My name is	How are
you? When we talked recently, I let you know Prostate, Lung, Colorectal and Ovarian (Freceive their cancer screenings, I will call you	ow that, as part of a research PLCO) Cancer Screening ou on a monthly basis to se	ch project to help Trial participants erve as a resource
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SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE
TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE
CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your PSA test when you came to our PLCO clinic • last year • two years ago • last year and two years ago.
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ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

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SCRIPT FOR AT2 MALE

ANNUAL SCHEDULING CALL

Hello, is this Mr.	? My name is	How are
you? When we talked recently, I	let you know that, as part of a research	project to help
Prostate, Lung, Colorectal and (Ovarian (PLCO) Cancer Screening Tri-	al participants
receive their cancer screenings, I	will call you on a monthly basis to serve	e as a resource
person, to help to find answers to	o your questions about things such as S	ocial Security,
Medicare, or other health issues.	I could even assist you with questions co	oncerning your
friends, children, and grandchildre	n.	
:		
Mr, I would like to sched	dule you for this year's free cancer screen	ing exams.
	th cancer of the prostate, lung, colon or re	
	CONTINUE BUT DO NOT OFFER OR	SCHEDULE
AN EXAM OF THAT PLCO ORG	GAN.	

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads.
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as <u>(read from the overview)</u>. Is that correct? And is your physician Dr. <u>(from the overview)</u> at <u>(address and city)</u>?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

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Were you able to find the information you were looking for? IF
PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you
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IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is How are you? When we
talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms.
_____, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about _____. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes; transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR A T2 MALE

ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr.	?	My name is _		I'ı	m cai	lling
from the PLCO study at Henry Ford Hospital.	I	would like to	schedule	this ye	ear's	free
cancer screening exams.						

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum? IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads.
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE #-AND PID)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as <u>(read from the overview)</u>. Is that correct? And is your physician Dr. <u>(from the overview)</u> at <u>(address and city)</u>?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. _____, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr, is your spouse/partner available now? I would like to introduce myself to				
them, so that when I call, they will know who I am. I can also assist your spouse/partner				
with questions they may have as well.				
Hello, Ms? My name is I am a Henry Ford Health				
System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer				
Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as				
a resource person, to help to find answers to questions about things such as Social				
Security, Medicare, health issues or other concerns. I could even assist with questions				
concerning your friends, children, and grandchildren. I would like to let you know that I				
would like to serve as a resource person for you as well as Mr When I call, if				
you have questions, please let me know, and I will do my best to find answers and				
solutions. Please feel free to ask me questions about anything.				

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T3 MALE

INTRODUCTORY TELEPHONE CALL

Hello, is this Mr.	? My name is	As part of a
research project to help Prostate, Lung,	Colorectal and Ovarian	(PLCO) Cancer
Screening Trial participants receive their can	cer screenings, I have been	assigned to assist
you in receiving your screenings. I would li	ke to call you on a monthly	y basis to serve as
a resource person, to help to find answers to	your questions about thir	igs such as Social
Security, Medicare, health issues or other	concerns. I could even	assist you with
questions concerning your friends, children, a		,

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much
for your time. I look forward to talking with you in the future.
Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T3 MALE

FIRST MONTH

Hello, is this Mr.	?	My name is		How are
you? When we talked recently, I let you	u know th	at, as part of a	research proje	ect to help
Prostate, Lung, Colorectal and Ovaria	in (PLCO) Cancer Scre	ening Trial pa	articipants
receive their cancer screenings, I will ca	all you on	a monthly bas	sis to serve as	a resource
person, to help to find answers to your	question	s about things	such as Social	Security.
Medicare, or other health issues. I could	d even ass	ist you with qu	uestions concer	ning your
friends, children, and grandchildren.				
Some of the people I've talked to recentl	v have me	entioned conce	rne about their	haalth as
the health of their family members and fi	riends, the	health care the	ov receive safe	nearm or
transportation, chore services for seniors	. child car	e. education of	themselves or	their
family members, finances and financial a	assistance.	food/nutrition	housing legal	aid
depression, anger, religion, substance ab			, nouning, logu	. u.u. ,
			•	
Are any of these things (or other things)	a concern	for you?	•	
WRITE DOWN THE THINGS TH	E PERS	SON STATES	S. TRY TO	O FIND
INFORMATION IN OUR FILES TO	HELP T	HE PERSON	WHILE YOU	J HAVE
THEM ON THE TELEPHONE. GIVE:	THE PER	SON THE REI	EVANT TEL	EPHONE
NUMBER(S). STATE:				
Mr von martia-ad	77	•	.1	. • •
Mr, you mentioned	I ner	e is an agency	,, that	t helps to
I would like to give you the ag more information. Do you have a pen?	Lloro is	the telephone	r so that you ca	n call for
WE HAVE AN IDENTIFIED CONTAC	TET TA	THE REPRODE	number:	If
blease ask for Mr./Ms	IAIII	E AGENCI, S	TATE: When	you can,
Do you have any other concerns you wou	ıld like to	discuss today?	(PROBE AGA	AIN FOR
SPECIFIC CONCERNS. WRITE T	HEM DO	DWN AND 7	TRY TO FIN	ID THE
TELEPHONE NUMBER OF SOMEON	IE WHO	CAN HELP T	O ADDRESS	THOSE
CONCERNS).				

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS STATE: Mr, I have noticed that you have had all of your PLCO screening that you have been scheduled for. I would like to commend you for this! We are interested in what keeps people involved in projects such as the PLCO Trial. What thing were helpful to you in getting your scheduled screenings?
WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. M. , we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your PSA test when you came to our PLCO clinic • last year • two years ago
three years agolast year and two years ago
last year and three years ago
two years ago and three years ago
 last year, two years ago, and three years ago.
Was there something that kept you from getting this exam
last year
two years ago
three years ago
 last year and two years ago
 last year and three years ago
 two years ago and three years ago
last year, two years ago, and three years ago?
(PROBE FOR BARRIERS: Sometimes people say that kept them from getting their PSA test. Was this something that you experienced? What kept you from getting your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THE PSA TEST. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT, DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your chest x-ray when you came to our PLCO clinic last year two years ago three years ago last year and two years ago last year and three years ago

- two years ago and three years ago
- last year, two years ago, and three years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

PROBE FOR BARRIERS: Sometimes people say that kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. , I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic • three years ago.
Was there something that kept you from getting this exam • three years ago?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your digital rectal exam when you came to our PLCO clinic • last year

- two years ago
- three years ago
- last year and two years ago
- last year and three years ago

- two years ago and three years ago
- last year, two years ago, and three years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

PROBE FOR BARRIERS: Sometimes people say that kept them from getting their digital rectal exam. Was this something that you experienced? What kept you from getting your digital rectal exam? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR DIGITAL RECTAL EXAM STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings • last year • two years ago

- three years ago
- last year and two years ago
- last year and three years ago
- two years ago and three years ago
- last year, two years ago, and three years ago?

Mr. _____, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray (for smokers only), and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is How are you? When we
? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.
Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.
Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that heips to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF
WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. _____. If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT3 MALE

SECOND MONTH

Hello, is this Mr. you? When we talked recently, I let you Prostate, Lung, Colorectal and Ovariar receive their cancer screenings, I will ca person, to help to find answers to your Medicare, or other health issues. I could friends, children, and grandchildren.	know that, as part of a resent (PLCO) Cancer Screening Il you on a monthly basis to questions about things such	arch project to help g Trial participants serve as a resource as Social Security,
Mr, when we talked last month Were you able to find the participant was able to FIND were able to have your questions answer PART OF SCRIPT.	ne information you were THE INFORMATION, STA	looking for? IF ATE: I'm glad you
IF PARTICIPANT WAS NOT ABLE TADDRESS THEIR CONCERNS, STATES answered/your concerns were not address answers. While I have you on the telephonave more information on this topic.	TE: I am sorry that your of sed. I would like to assist y	questions were not ou in finding some
IF YOU DON'T HAVE ANY MORE IN, I will call you back later with ac we talked last month, you also mentioned you able to find the information you were TO FIND THE INFORMATION, STA questions answered/your concerns address	dditional information. Before that you were concerned able looking for? IF PARTICIFATE: I'm glad you were	e we hang up, when yout Were PANT WAS ABLE able to have your
F PARTICIPANT WAS NOT ABLE TADDRESS THEIR CONCERNS, STATEMENT OF THE STATE	TE: I am sorry that your obssed. IF YOU DON'T HA	questions were not AVE ANY MORE

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

TRY TO FIND

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES.

INFORMATION IN OUR FILES TO HELP THEM ON THE TELEPHONE. GIVE THE PE	
NUMBER(S). STATE:	
Mr, you mentioned The I would like to give you the agency's more information. Do you have a pen? Here WE HAVE AN IDENTIFIED CONTACT AT The please ask for Mr./Ms	telephone number so that you can call for is the telephone number:
Do you have any other concerns you would like to SPECIFIC CONCERNS. WRITE THEM TELEPHONE NUMBER OF SOMEONE WHO CONCERNS).	DOWN AND TRY TO FIND THE

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr.
, when we talked last month, I noticed that you have had all of your PLCO
screenings that you have been scheduled for. I would like to commend you again for
screenings that you have been screening for a would like to commend you again for
this! Mr, we will do our best to make sure that you continue to have a positive
experience in the PLCO Trial. GO TO NEXT QUESTION.
A TEST DIRECT AND A PARTY OF THE REAL TEST DIRECT DIRECT AND A PARTY OF THE REAL TEST DIRECT DIR
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A
PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we
talked last month, you mentioned, that kept you from getting your PSA test
when you came to our PLCO clinic
• last year
two years ago
three years ago
 last year and two years ago
 last year and three years ago
 two years ago and three years ago
 last year, two years ago, and three years ago.
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• last year
two years agothree years ago
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last year and three years ago
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(PROBE FOR BARRIERS.)
Mr, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your PLCO screenings. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? These screenings include the PSA test, a chest x-ray (for smokers only), and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month. SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is ... How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. _____, when we talked last month, you mentioned that you were concerned about _____. Were you able to find the information IF SPOUSE/PARTNER WAS ABLE TO FIND THE you were looking for? I'm glad you were able to have your questions INFORMATION, STATE: answered/vour concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. , I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
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Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT3 MALE

THIRD MONTH

Hello, is this Mr.	? My	name is	. How are
you? When we talked recently, I let yo Prostate, Lung, Colorectal and Ovaria receive their cancer screenings, I will c person, to help to find answers to you	ou know that, as an (PLCO) Car all you on a mo	s part of a research neer Screening Tronthly basis to ser-	n project to help rial participants ve as a resource
Medicare, or other health issues. I coul friends, children, and grandchildren.	d even assist yo	ou with questions	concerning your
Mr, when we talked last month were you able to find PARTICIPANT WAS ABLE TO FINE were able to have your questions answere PART OF SCRIPT.	the information THE INFORM	n you were loo! MATION, STATE	king for? IF : I'm glad you
IF PARTICIPANT WAS NOT ABLE ADDRESS THEIR CONCERNS, STA answered/your concerns were not addre answers. While I have you on the telephave more information on this topic.	ATE: I am sor	rry that your ques like to assist you i	stions were not in finding some
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Are any of these things (or other things) a concern for you?

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Mr										
	I would l	ike to giv	e you the	agency	's telepl	none nu	mber s	o that yo	ou can	call for
more infor	mation.	Do you h	ave a pe	n? H	ere is th	e telepi	none nu	ımber:		IF
WE HAVE	E AN IDI	ENTIFIEI	O CONT	ACT A	T THE A	AGENC	Y, STA	ATE: W	hen yo	ou call.
please ask	for Mr./N	⁄Is		·					•	
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Do you hav	ve any ot	her conce	rns you v	would li	ke to dis	cuss to	day? (I	PROBE	AGAI	N FOR
SPECIFIC	CONC	ERNS.	WRITE	THEN	M DOW	N AN	ID TR	Y TO	FIND	THE
TELEPHO	NE NUI	MBER O	F SOME	ONE V	VHO CA	AN HE	LP TO	ADDR	ESS T	HOSE
CONCERN										

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS, DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr.				
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ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

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SCRIPT FOR AT3 MALE

ANNUAL SCHEDULING CALL

Hello, is this Mr.	? My name is	How are
you? When we talked recently, I let yo	u know that, as part of a resea	irch project to help
Prostate, Lung, Colorectal and Ovaria	, ,	
receive their cancer screenings, I will c	•	
person, to help to find answers to your		
Medicare, or other health issues. I coul	d even assist you with question	ns concerning your
friends, children, and grandchildren.		
Mr, I would like to schedule y	ou for this year's free cancer so	reening exams.
First, have you been diagnosed with can	cer of the prostate, lung, colon	or rectum?
IF NO, CONTINUE. IF YES, CONT	INUE BUT DO NOT OFFER	OR SCHEDULE
AN EXAM OF THAT PLCO ORGAN.		
Have you ever smoked cigarettes, cigar	rs or a pipe on a regular basis	for six months or

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

longer? IF NO, DO NOT OFFER OR SCHEDULE THE CHEST X-RAY. IF YES,

A blood test

CONTINUE (OFFER AND SCHEDULE THE CHEST X-RAY.)

- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID, AND INDICATE WHETHER THE PERSON IS A NON-SMOKER OR A SMOKER.)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as <u>(read from the overview)</u>. Is that correct? And is your physician Dr. <u>(from the overview)</u> at <u>(address and city)</u>?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancerfree prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Whit _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.
IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FINI INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Mr, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: If WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
ASK: Mr, did you have any other questions or concerns about something in your own life or the lives of your family or friends?
IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is How are you? When we
talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms, when we talked last zhouth, you mentioned that you were concerned about Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms.

_____, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about _____. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR A T3 MALE

ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr.	_?	My name is	I'm callin	ng
from the PLCO study at Henry Ford Hospital	1.	I would like to schedule this	year's fr	ee
cancer screening exams.			•	

First, have you been diagnosed with cancer of the prostate, lung, colon or rectum? IF NO, CONTINUE. IF YES, CONTINUE BUT DO NOT OFFER OR SCHEDULE AN EXAM OF THAT PLCO ORGAN.

Have you ever smoked cigarettes, cigars or a pipe on a regular basis for six months or longer? IF NO, DO NOT OFFER OR SCHEDULE THE CHEST X-RAY. IF YES, CONTINUE (OFFER AND SCHEDULE THE CHEST X-RAY.)

This year, there is no sigmoidoscopy, so no preparation is involved, but you will receive:

- A blood test
- A Chest x-ray
- And an exam of the prostate

Your appointment will take about an hour and all of the exams will be done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads.
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE NON-SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID, AND INDICATE WHETHER THE PERSON IS A NON-SMOKER OR A SMOKER.)

We will send a letter confirming the day, date, time, and the location with a map, and after the exams are done we will send a copy of the results to both you and your physician.

We have your address as <u>(read from the overview)</u>. Is that correct? And is your physician Dr. <u>(from the overview)</u> at <u>(address and city)</u>?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings include the PSA test, a chest x-ray, and a digital rectal exam.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you. If there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. _____, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr, is your spouse/partner available now? them, so that when I call, they will know who I am. with questions they may have as well.	I would like to introduce myself to I can also assist your spouse/partner
Hello, Ms? My name is System employee working on the Prostate, Lung Screening Trial. I would like to call your (spouse/par a resource person, to help to find answers to ques Security, Medicare, health issues or other concerns. concerning your friends, children, and grandchildren. would like to serve as a resource person for you as we you have questions, please let me know, and I will solutions. Please feel free to ask me questions about a	ther) on a monthly basis to serve as stions about things such as Social I could even assist with questions I would like to let you know that I well as Mr When I call, if I do my best to find answers and

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T4 MALE

INTRODUCTORY TELEPHONE CALL

Hello, is this Mr.				? My nar	ne is _		As	part of a
research project	to help	Prostate,	Lung,	Colorectal	and	Ovarian	(PLCO)	Cancer
Screening Trial pa	erticipants	s receive th	eir cand	er screening	gs, I h	ave been	assigned	to assist
you in receiving y	our scree	nings. I w	ould lik	ce to call yo	u on a	monthly	basis to	serve as
a resource person,	, to help	to find ans	wers to	your quest	ions a	bout thin	gs such a	s Social
Security, Medicar	re, health	issues or	other	concerns.	I co	uld even	assist y	ou with
questions concerni	ing your f	friends, chi	ldren, a	nd grandchi	ildren.		•	

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.
Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T4 MALE

FIRST MONTH

Hello, is this Mr? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security. Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.
Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.
Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Mr, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENING	S,
STATE: Mr, I have noticed that you have had all of your PLCO screening	zs
that you have been scheduled for. I would like to commend you for this! We a	re
interested in what keeps people involved in projects such as the PLCO Trial. What thing	zs
were helpful to you in getting your scheduled screenings?	

WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr. we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. _____, I see that you did not get your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

PROBE FOR BARRIERS: Sometimes people say that _	kept them from getting
their PSA test. Was this something that you experienced?	What kept you from getting
your PSA test? WRITE DOWN THE THINGS THE PA	ARTICIPANT SAYS KEPT
THEM FROM GETTING THE PSA TEST. STATE: Mr.	, I understand what
you are saying. I would like to work with you so that	will not keep you from
getting your PSA test. RESPOND TO THE BARRIER(
PARTICIPANT AND ADDRESS THEM.	

IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. _____, I see that you did not get your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

PROBE FOR BARRIERS: Sometimes people say that ____ kept them from getting their chest x-ray. Was this something that you experienced? What kept you from getting your

chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR CHEST X-RAY. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic • four years ago.
Was there something that kept you from getting this exam • four years ago?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their flexible sigmoidoscopies. Was this something that you experienced? What kept you from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE SIGMOIDOSCOPY. STATE: Mr, I understand what you are saying. I would like to work with you so that will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I see that you did not get your digital rectal exam when you came to our PLCO clinic
 last year two years ago three years ago four years ago last year, two years ago, and three years ago last year, two years ago, and four years ago last year, three years ago, and four years ago last year and two years ago
 last year and three years ago last year and four years ago last year two years ago, three years ago, and four years ago

• two years ago, three years ago, and four years ago

Was there something that kept you from getting this exam

two years ago and three years ago
two years ago and four years ago
three years ago and four years ago.

- last year
- two years ago

- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

PROBE FOR BARR	IERS: Some	times people s	say that	kept them f	rom getting their
digital rectal exam.	Was this so	mething that	you experie	nced? Wha	kept you from
getting your digital r	ectal exam?	WRITE DOV	WN THE TH	IINGS THE	PARTICIPANT
SAYS KEPT THEM					
STATE: Mr.					
so that will no					
THE BARRIER(S) M	IENTIONED	BY THE PA	RTICIPAN1	AND ADD	RESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. _____, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

- last year
- two years ago
- three years ago
- four years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year, two years ago, three years ago, and four years ago
- two years ago, three years ago, and four years ago
- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

(PROBE FOR BARRIERS.)

Mr. _____, the information we gain from the PLCO Trial could help future generations of people. In addition, the findings related to prostate cancer may be particularly important to African American men. For these reasons, I would like to work with you to help to make your PLCO screenings as easy for you as possible. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

If PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is How are you? When we
? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren.
Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.
Are any of these things (or other things) a concern for you?
WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call,
please ask for Mr./Ms

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. _____. If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT4 MALE

SECOND MONTH

Hello, is this Mr? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.
Mr, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.
IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information.

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

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Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS,
DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr.
, when we talked last month, I noticed that you have had all of your PLCO
screenings that you have been scheduled for. I would like to commend you again for
this! Mr, we will do our best to make sure that you continue to have a positive
experience in the PLCO Trial. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A
PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we
talked last month, you mentioned, that kept you from getting your PSA test
when you came to our PLCO clinic
last year
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I would like to continue our discussion from last month about ways of dealing with these
things so that will not keep you from getting your PSA test. RESPOND TO
THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A
PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we
talked last month, you mentioned, that kept you from getting your chest x-ray
when you came to our PLCO clinic
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IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic four years ago.
I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your digital rectal exam when you came to our PLCO clinic • last year • two years ago
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I would like to continue our discussion from last month about ways of dealing with these things so that _____ will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

three years ago and four years ago.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCC
SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING
STATE: Mr, I would like to commend you for enrolling in the PLCO Trial
Your participation in this project is very important to us. We are interested in what keep
people from getting their scheduled PLCO screenings. When we talked last month, you
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our PLCO clinic

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- two years ago and three years ago
- two years ago and four years ago
- three years ago and four years ago?

(PROBE FOR BARRIERS.)

Mr. _____, do you have any questions about any of the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the live's of your family or friends?

IF PARTICIFANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

lives of their children, family or friends. I will call again next month. SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is . How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings. I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. _____, when we talked last month, you mentioned that you were concerned about _____. Were you able to find the information IF SPOUSE/PARTNER WAS ABLE TO FIND THE you were looking for? I'm glad you were able to have your questions INFORMATION, STATE: answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. , I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

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Are any of these things (or other things) a concern for you?

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NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to
. I would like to give you the agency's telephone number so that you can call for
more information. Do you have a pen? Here is the telephone number:
WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call,
please ask for Mr./Ms
•
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR
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THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE
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While I have you on the telephone, Ms, let me check my files to find some
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WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call,
please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today?
F NOT, STATE: It has been nice talking with you today, Ms If you have any
questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT4 MALE

THIRD MONTH

Hello, is this Mr. you? When we talked recently, I let you know Prostate, Lung, Colorectal and Ovarian (Preceive their cancer screenings, I will call you person, to help to find answers to your que Medicare, or other health issues. I could even friends, children, and grandchildren.	ow that, as part of a research project to he PLCO) Cancer Screening Trial participant on a monthly basis to serve as a resource stions about things such as Social Security
Mr, when we talked last month, you were you able to find the in PARTICIPANT WAS ABLE TO FIND THE were able to have your questions answered PART OF SCRIPT.	information you were looking for? I E INFORMATION, STATE: I'm glad yo
IF PARTICIPANT WAS NOT ABLE TO F ADDRESS THEIR CONCERNS, STATE: answered/your concerns were not addressed. answers. While I have you on the telephone, have more information on this topic.	I am sorry that your questions were not I would like to assist you in finding som
IF YOU DON'T HAVE ANY MORE INFORMATION, I will call you back later with addition we talked last month, you also mentioned that you able to find the information you were located to FIND THE INFORMATION, STATE: questions answered/your concerns addressed.	onal information. Before we hang up, when t you were concerned about Were oking for? IF PARTICIPANT WAS ABLE I'm glad you were able to have you
F PARTICIPANT WAS NOT ABLE TO F. ADDRESS THEIR CONCERNS, STATE: inswered/your concerns were not addressed NFORMATION ON THIS TOPIC, STATE with additional information.	I am sorry that your questions were no l. IF YOU DON'T HAVE ANY MORE

STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

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DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: MI
when we talked last month I noticed that were hard all of some DI Co
, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for
this! Mr, we will do our best to make sure that you continue to have a positive
experience in the PLCO Trial. GO TO NEXT QUESTION.
experience in the 1200 That. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A
PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we
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would like to continue our discussion from last month about ways of dealing with these
things so that will not keep you from getting your PSA test RESPOND TO
THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
T. DADWIGIDAN TO THE STATE OF T
F PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A
PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we
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	I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
	IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic four years ago.
	I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
	IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your digital rectal exam when you came to our PLCO clinic last year
Ι	would like to continue our discussion from last month about ways of dealing with these

things so that ____ will not keep you from getting your digital rectal exam.

RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND

ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO
SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING,
STATE: Mr, I would like to commend you for enrolling in the PLCO Trial!
Your participation in this project is very important to us. We are interested in what keeps
people from getting their scheduled PLCO screenings. When we talked last month, you
mentioned, that kept you from getting your PLCO screenings when you came to
our PLCO clinic

- last year
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Mr, the information we gain from the PLCO Trial could help future generations				
of people. In addition, the findings related to prostate cancer may be particularly				
important to African American men. For these reasons, I would like to work with you to				
help to make your PLCO screenings as easy for you as possible. I would like to continue				
our discussion from last month about ways of dealing with these things so that				
will not keep you from getting your digital rectal exam. RESPOND TO THE				
BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM				

Mr. _____, do you have any questions about any of the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

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ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know them I called and am available to talk with them

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Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT4 MALE

ANNUAL SCHEDULING CALL

Hello, is this Mr	know that, as part of a research (PLCO) Cancer Screening all you on a monthly basis to sequestions about things such as	ch project to help Trial participants rve as a resource Social Security,
Mr, I would like to schedule yo	u for this year's free cancer scre	eening exam.
First, I would like to ask Have you be colon or rectum?	een diagnosed with cancer of the	he prostate, lung,
F NO, CONTINUE. IF YES, CONT OVERVIEW AND ON THE SCHEDUL		ONSE ON THE
This year we would like to schedule you hould be approximately 15 minutes.	ou for a blood test only, and	the appointment
	orthwest Clinic, at Outer	

- Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which would be the most convenient for you?

At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.

Which is the best time for you?

(RECORD IN THE BLOOD AND X-RAY ONLY SLOT, ON THE OVERVIEW, PARTICIPANTS NAME, PHONE # AND PID #.)

We will send a letter confirming the day, date, time, and the location with a map . . .

IF NO PROSTATE OR IF CANCER IS REPORTED OF THE PROSTATE - NO RESULTS ARE MAILED... SKIP TO ADDRESS INFORMATION.

... and after the exam is done we will send a copy of the results to both you and your physician. We have your physician as Dr. (<u>from the overview</u>) at (<u>address and city</u>). Is that correct?

We have your address as (read from the overview). Is that correct?

Mr. _____, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you arrive waik through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.
IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Mr, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
ASK: Mr, did you have any other questions or concerns about something in your own life or the lives of your family or friends?
IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is How are you? When we
talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about _____. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

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STATE: Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes, transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid, depression, anger, religion, substance abuse, transportation, etc.

Are any of these things (or other things) a concern for you?

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Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR A T4 MALE

ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT
Hello, is this Mr? My name is I'm calling from the PLCO study at Henry Ford Hospital. I would like to schedule this year's free cancer screening exams.
First, I would like to ask Have you been diagnosed with cancer of the prostate, lung, colon or rectum?
IF NO, CONTINUE. IF YES, CONTINUE AND RECORD RESPONSE ON THE OVERVIEW AND ON THE SCHEDULE.
This year we would like to schedule you for a blood test only, and the appointment should be approximately 15 minutes.
 We do these exams at three locations: Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads, Our Fairlane location in Dearborn near the Fairlane shopping mall, and Our Downriver Clinic, on Allen Road, off of I-75 North.
Which would be the most convenient for you?
At the (designated clinic) I have day, month, and date at time in the morning or time in the afternoon.
Which is the best time for you?
(RECORD IN THE BLOOD AND X-RAY ONLY SLOT, ON THE OVERVIEW, PARTICIPANTS NAME, PHONE # AND PID #.)
We will send a letter confirming the day, date, time, and the location with a map
IF NO PROSTATE OR IF CANCER IS REPORTED OF THE PROSTATE - NO RESULTS ARE MAILED SKIP TO ADDRESS INFORMATION.

... and after the exam is done we will send a copy of the results to both you and your physician. We have your physician as Dr. (from the overview) at (address and city). Is

that correct?

We have your address as (read from the overview). Is that correct?

Mr. _____, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize – enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. _____, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr, is your spouse/partner available now? I would like to introduce myself them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.	ner
Hello, Ms? My name is I am a Henry Ford Hear System employee working on the Prostate, Lung, Colorectal, and Ovarian Cand Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve a resource person, to help to find answers to questions about things such as Soc Security, Medicare, health issues or other concerns. I could even assist with questic concerning your friends, children, and grandchildren. I would like to let you know that would like to serve as a resource person for you as well as Mr When I call you have questions, please let me know, and I will do my best to find answers a solutions. Please feel free to ask me questions about anything.	cer as cial ons at I

All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T5 MALE

INTRODUCTORY TELEPHONE CALL

Hello, is this Mr.				? My nar	ne is _		As	part of a
research project	to help	Prostate,	Lung,	Colorectal	and	Ovarian	(PLCO)	Cancer
Screening Trial pa	articipants	receive th	eir cand	er screening	gs, I h	ave been	assigned	to assist
you in receiving y	our scree	nings. I w	ould lik	te to call yo	u on a	a monthly	basis to	serve as
a resource person	, to help t	to find ans	wers to	your questi	ions a	bout thin	gs such a	as Social
Security, Medica	re, health	issues or	other	concerns.	I co	uld even	assist y	ou with
questions concern							•	

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.
Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partner with questions they may have as well.
Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.
All right. Have a nice day. I look forward to talking with you soon.

SCRIPT FOR A T5 MALE

FIRST MONTH ? My name is _____. How are Hello, is this Mr. you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security. Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren. Some of the people I've talked to recently have mentioned concerns about their health or the health of their family members and friends, the health care they receive, safety, taxes. transportation, chore services for seniors, child care, education of themselves or their family members, finances and financial assistance, food/nutrition, housing, legal aid. depression, anger, religion, substance abuse, transportation, etc. Are any of these things (or other things) a concern for you? WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: Mr. _____, you mentioned _____. There is an agency, _____, that helps to . I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: _____. IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms.

Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS,
STATE: Mr, I have noticed that you have had all of your PLCO screenings
that you have been scheduled for. I would like to commend you for this! We are
interested in what keeps people involved in projects such as the PLCO Trial. What things
were helpful to you in getting your scheduled screenings?
WRITE DOWN THE THINGS THE PARTICIPANT SAYS WERE HELPFUL. Mr.
, we will do our best to make sure that you continue to have a positive
experience in the PLCO Trial GO TO NEXT OUESTION

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. _____, I see that you did not get your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
- last year, three years ago, four years ago, and five years ago
- last year, two years ago, three years ago, and four years ago
- last year, two years ago, and five years ago
- last year, two years ago, four years ago, and five years ago
- last year, three years ago, and five years ago
- last year, two years ago, three years ago, and five years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year, four years ago, and five years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year and five years ago
- two years ago, three years ago, four years ago, and five years ago
- two years ago, three years ago, and four years ago
- two years ago, three years ago, and five years ago
- two years ago and three years ago
- two years ago, four years ago, and five years ago
- · two years ago and four years ago
- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago.

Was there something that kept you from getting this exam

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
- last year, three years ago, four years ago, and five years ago
- last year, two years ago, three years ago, and four years ago
- last year, two years ago, and five years ago
- last year, two years ago, four years ago, and five years ago
- last year, three years ago, and five years ago
- last year, two years ago, three years ago, and five years ago
- last year, two years ago, and three years ago
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- · three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

(PRORE FOR BARRIERS: Sometimes meanle say that

(110000 1010 Di Hadabias. Boineannes people say that kept them from getting
their PSA test. Was this something that you experienced? What kept you from getting
your PSA test? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT
THEM FROM GETTING THE PSA TEST. STATE: Mr, I understand what
you are saying. I would like to work with you so that will not keep you from
getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE
PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A
PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. , I see that
you did not get your chest x-ray when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
- last year, three years ago, four years ago, and five years ago
- last year, two years ago, three years ago, and four years ago
- last year, two years ago, and five years ago
- last year, two years ago, four years ago, and five years ago
- last year, three years ago, and five years ago
- last year, two years ago, three years ago, and five years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year, four years ago, and five years ago
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- two years ago, three years ago, and five years ago
- two years ago and three years ago
- two years ago, four years ago, and five years ago
- two years ago and four years ago
- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago.

Was there something that kept you from getting this exam

- last vear
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
- last year, three years ago, four years ago, and five years ago —
- last year, two years ago, three years ago, and four years ago
- last year, two years ago, and five years ago
- last year, two years ago, four years ago, and five years ago
- last year, three years ago, and five years ago

- last year, two years ago, three years ago, and five years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year, four years ago, and five years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year and five years ago
- two years ago, three years ago, four years ago, and five years ago
- two years ago, three years ago, and four years ago
- two years ago, three years ago, and five years ago
- two years ago and three years ago
- two years ago, four years ago, and five years ago
- two years ago and four years ago
- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

PROBE FOR BARRIERS: Sometimes people say that kept them from getting their
chest x-ray. Was this something that you experienced? What kept you from getting your
chest x-ray? WRITE DOWN THE THINGS THE PARTICIPANT SAYS KEPT THEM
FROM GETTING THEIR CHEST X-RAY. STATE: Mr, I understand what
you are saying. I would like to work with you so that will not keep you from
getting your chest x-ray. RESPOND TO THE BARRIER(S) MENTIONED BY THE
PARTICIPANT AND ADDRESS THEM.
IE DADTICIDANT DID NOT ADJEDE TO THE ELEVIDLE GLOVODOGODY
IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY
DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr.
, I see that you did not get your flexible sigmoidoscopy when you came to our PLCO clinic
• five years ago.
inve years ago.
Was there something that kept you from getting this exam
• five years ago?
PROBE FOR BARRIERS: Sometimes people say that kept them from getting their
flexible sigmoidoscopies. Was this something that you experienced? What kept you
from getting your flexible sigmoidoscopy? WRITE DOWN THE THINGS THE
PARTICIPANT SAYS KEPT THEM FROM GETTING THEIR FLEXIBLE
SIGMOIDOSCOPY. STATE: Mr, I understand what you are saying. I would
like to work with you so that will not keep you from getting your flexible
sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE
PARTICIPANT AND ADDRESS THEM.

IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. _____, I see that you did not get your digital rectal exam when you came to our PLCO clinic

- two years ago
- three years ago
- four years ago
- five years ago
- two years ago, three years ago, four years ago, and five years ago
- two years ago, four years ago, and five years ago
- two years ago, three years ago, and four years ago
- two years ago, three years ago, and five years ago
- two years ago and three years ago
- two years ago and four years ago
- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and five years ago
- three years ago and four years ago
- four years ago and five years ago.

Was there something that kept you from getting this exam

- two years ago
- three years ago
- four years ago
- five years ago
- two years ago, three years ago, four years ago, and five years ago
- two years ago, four years ago, and five years ago
- two years ago, three years ago, and four years ago
- two years ago, three years ago, and five years ago
- two years ago and three years ago
- two years ago and four years ago
- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and five years ago
- three years ago and four years ago
- four years ago and five years ago?

PROBE FOR BARRIERS:	Sometimes people say	that kept 1	them from ge	tting their
digital rectal exam. Was the	his something that yo	u experienced?	What kept	you from
getting your digital rectal ex				
SAYS KEPT THEM FROM				
STATE: Mr, I und	derstand what you are	saying. I would	like to work	with you
so that will not keep	you from getting you	r digital rectal e	xam. RESP	CND TO
THE BARRIER(S) MENTIC	ONED BY THE PART	ICIPANT AND	ADDRESS'	ГНЕМ.

IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING.

STATE: Mr. _____, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. What things kept you from getting your scheduled screenings

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
- last year, three years ago, four years ago, and five years ago
- last year, two years ago, three years ago, and four years ago
- last year, two years ago, and five years ago
- last year, two years ago, four years ago, and five years ago
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- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
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- last year, four years ago, and five years ago
- last year and two years ago
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- two years ago, three years ago, and five years ago
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- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

(PROBE FOR BARRIERS)

Mr	, the information we gain from the PLCO Trial could help future generations
	In addition, the findings related to prostate cancer may be particularly
important to	African American men. For these reasons, I would like to work with you to
help to make	e your PLCO screenings as easy for you as possible. RESPOND TO THE
BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings will consist of the PSA test and a flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms. _____. If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT5 MALE

SECOND MONTH

Hello, is this Mr? My name is How you? When we talked recently, I let you know that, as part of a research project to I Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participarteceive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Secur Medicare, or other health issues. I could even assist you with questions concerning y friends, children, and grandchildren.	help ant: irco
Mr, when we talked last month, you mentioned that you were concerned ab Were you able to find the information you were looking for? PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad y were able to have your questions answered/your concerns addressed. GO TO NE PART OF SCRIPT.	IF
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED. ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were answered/your concerns were not addressed. I would like to assist you in finding so answers. While I have you on the telephone, I will check my files again to see whether have more information on this topic.	not
IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: New York and I will call you back later with additional information. Before we hang up, who we talked last month, you also mentioned that you were concerned about We you able to find the information you were looking for? IF PARTICIPANT WAS ABITO FIND THE INFORMATION, STATE: I'm glad you were able to have yo questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.	en ere
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORINFORMATION ON THIS TOPIC, STATE: Mr, I will call you back lat with additional information.	ot

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INFORM	IATION IN O	UR FILES TO	HELP THE	PERSON W	HILE YOU	HAV
THEM O	N THE TELEP	HONE. GIVE	THE PERSON	THE RELEV	ANT TELE	PHONI
	R(S). STATE:					
Mr.	, you me	ntioned	. There is	an agency,	, that	helps to
	I would like to	give you the ag	ency's telepho	one number so	that you car	call for
more info	rmation. Do y	ou have a pen?	Here is the	telephone nur	nber:	. II
WE HAV	E AN IDENTI	FIED CONTAC	T AT THE A	GENCY, STA	TE: When	ou call
	for Mr./Ms			·	•	
Do you ha	ave any other co	oncerns you wou	ald like to disc	uss today? (P.	ROBE AGA	IN FOR
SPECIFIC	CONCERNS	S. WRITE T	HEM DOWN	N AND TRY	Y TO FINI	O THE
TELEPHO	ONE NUMBE	R OF SOMEON	E WHO CA	N HELP TO	ADDRESS '	THOSE
CONCER	NS)					

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS. DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, I noticed that you have had all of your PLCO screenings that you have been scheduled for. I would like to commend you again for this! Mr, we will do our best to make sure that you continue to have a positive experience in the PLCO Trial. GO TO NEXT QUESTION.
IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your PSA test when you came to our PLCO clinic • last year
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Tom Jones and min are Jones and

I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest x-ray when you came to our PLCO clinic
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I would like to continue our discussion from last mouth about ways of dealing with these
things so that will not keep you from getting your chest x-ray. RESPOND TO
THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.

DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr.
when we talked last month, you mentioned, that kept you from getting you chest flexible sigmoidoscopy when you came to our PLCO clinic
• five years ago.
I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your flexible sigmoidoscopy RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we
talked last month, you mentioned, that kept you from getting your digital rectal exam when you came to our PLCO clinic
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three years ago and four years ago
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I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your digital rectal even
RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO ANY OF THE SCHEDULED PLCO
SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING,
STATE: Mr, I would like to commend you for enrolling in the PLCO Trial!
Your participation in this project is very important to us. We are interested in what keeps
people from getting their scheduled PLCO screenings. When we talked last month, you
mentioned, that kept you from getting your PLCO screenings when you came to
our PLCO clinic
last year
two years ago
three years ago

- four years ago
- five years ago
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- last year, two years ago, three years ago, and four years ago
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- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings will consist of the PSA test and the flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

lives of their children, family or friends. I will call again next month. SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. . How are you? When we ? My name is talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. , when we talked last month, you mentioned that you were concerned about _____. Were you able to find the information IF SPOUSE/PARTNER WAS ABLE TO FIND THE you were looking for? I'm glad you were able to have your questions INFORMATION, STATE: answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. , I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information

about any questions or concerns they may have about something in their own lives or the

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND

THEM ON THE TELEPHONE. GIVE THE PERSON WHILE YOU HAV NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps tegency is the second of the s
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS. THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELD THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call formore information. Do you have a pen? Here is the telephone number: WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? IF NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT5 MALE

THIRD MONTH

Hello, is this Mr? My name is How are you? When we talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security Medicare, or other health issues. I could even assist you with questions concerning your friends, children, and grandchildren.
Mr, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.
IF PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.
IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Mr. J. I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about Output O
F PARTICIPANT WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not nswered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE NFORMATION ON THIS TOPIC, STATE: Mr, I will call you back later with additional information.

WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FINI
INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE
THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE
NUMBER(S). STATE:
Mr, you mentioned There is an agency,, that helps to
. I would like to give you the agency's telephone number so that you can call for
more information. Do you have a pen? Here is the telephone number.
WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call.
please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR
SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE
TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE
CONCERNS).

IF PARTICIPANT ADHERED TO ALL PREVIOUSLY SCHEDULED SCREENINGS
DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr
, when we talked last month, I noticed that you have had all of your PLCC
screenings that you have been scheduled for. I would like to commend you again for
this! Mr, we will do our best to make sure that you continue to have a positive
experience in the PLCO Trial. GO TO NEXT QUESTION.

IF PARTICIPANT DID NOT ADHERE TO THE PSA TEST DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr. ____, when we talked last month, you mentioned _____, that kept you from getting your PSA test when you came to our PLCO clinic

- last year
- two years ago
- three years ago
- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years ago
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- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year, four years ago, and five years ago
- last year and two years ago
- last year and three years ago
- last year and four years ago
- last year and five years ago
- two years ago, three years ago, four years ago, and five years ago
- two years ago, three years ago, and four years ago
- two years ago, three years ago, and five years ago
- two years ago and three years ago
- two years ago, four years ago, and five years ago
- two years ago and four years ago
- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your PSA test. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE CHEST X-RAY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest x-ray when you came to our PLCO clinic
last year
two years ago
three years ago
four years ago
five years ago
 last year, two years ago, three years ago, four years ago, and five years
ago
 last year, three years ago, four years ago, and five years ago
 last year, two years ago, three years ago, and four years ago
 last year, two years ago, and five years ago
 last year, two years ago, four years ago, and five years ago
 last year, three years ago, and five years ago
 last year, two years ago, three years ago, and five years ago
 last year, two years ago, and three years ago
 last year, two years ago, and four years ago
 last year, three years ago, and four years ago
 last year, four years ago, and five years ago
last year and two years ago
last year and three years ago
last year and four years ago
last year and five years ago
two years ago, three years ago, four years ago, and five years ago
• two years ago, three years ago, and four years ago
two years ago, three years ago, and five years ago
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two years ago and five years ago
• three years ago, four years ago, and five years ago
• three years ago and four years ago
three years ago and five years ago
• four years ago and five years ago?
Tom yours ago and rive yours ago.
would like to continue our discussion from last month about ways of dealing with these
things so that will not keep you from getting your chest x-ray. RESPOND TO
THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
The Diagram of the Internation and Addition (1).

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IF PARTICIPANT DID NOT ADHERE TO THE FLEXIBLE SIGMOIDOSCOPY DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your chest flexible sigmoidoscopy when you came to our PLCO clinic • five years ago.
I would like to continue our discussion from last month about ways of dealing with these things so that will not keep you from getting your flexible sigmoidoscopy. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
IF PARTICIPANT DID NOT ADHERE TO THE DIGITAL RECTAL EXAM DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, when we talked last month, you mentioned, that kept you from getting your digital rectal exam when you came to our PLCO clinic • two years ago
 three years ago four years ago five years ago two years ago, three years ago, four years ago, and five years ago
 two years ago, four years ago, and five years ago two years ago, three years ago, and four years ago two years ago, three years ago, and five years ago two years ago and three years ago
 two years ago and four years ago two years ago and five years ago three years ago, four years ago, and five years ago three years ago and five years ago
three years ago and four years ago four years ago and five years ago I would like to continue our discussion from last month about ways of dealing with these
things so that will not keep you from getting your digital rectal exam. RESPOND TO THE BARRIER(S) MENTIONED BY THE PARTICIPANT AND ADDRESS THEM.
SCREENINGS DURING A PREVIOUSLY SCHEDULED PLCO SCREENING, STATE: Mr, I would like to commend you for enrolling in the PLCO Trial! Your participation in this project is very important to us. We are interested in what keeps people from getting their scheduled PLCO screenings. When we talked last month, you mentioned, that kept you from getting your PLCO screenings when you came to our PLCO clinic

- last year
- two years ago
- three years ago

- four years ago
- five years ago
- last year, two years ago, three years ago, four years ago, and five years
- last year, three years ago, four years ago, and five years ago
- last year, two years ago, three years ago, and four years ago
- last year, two years ago, and five years ago
- last year, two years ago, four years ago, and five years ago
- last year, three years ago, and five years ago
- last year, two years ago, three years ago, and five years ago
- last year, two years ago, and three years ago
- last year, two years ago, and four years ago
- last year, three years ago, and four years ago
- last year, four years ago, and five years ago
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- two years ago, three years ago, four years ago, and five years ago
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- two years ago and five years ago
- three years ago, four years ago, and five years ago
- three years ago and four years ago
- three years ago and five years ago
- four years ago and five years ago?

Mr	, the info	rmation v	ve gain fro	om the PI	.CO Tria	l could	help fut	ture g	enera	itions
of people.										
important to	African A	merican	men. Fo	r these re	asons, I v	would l	ike to w	ork v	vith y	ou to
help to make	e your PL	CO scree	nings as e	asy for yo	ou as pos	sible. I	would	like t	o con	tinue
our discussion	on from la	st month	about wa	ys of dea	ling with	these	things s	o tha	t	
will not ke	ep you	from get	tting you	r digital	rectal	exam.	RESPO	ND	TO	THE
BARRIER(S	S) MENTI	ONED B	Y THE P.	ARTICIP	ANT AN	ID AD	DRESS	THE	M.	

Mr. _____, do you have any questions about any of the PLCO screenings you will receive this year? Again, these screenings will consist of the PSA test and a flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK: Mr. ____, did you have any other questions or concerns about something in your own life or the lives of your family or friends?

IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr. _____. If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them

about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month. SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. . How are you? When we ? My name is talked recently, I let you know that, as part of a research project to help Prostate. Lung. Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security. Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms. _____, when we talked last month, you mentioned that you were concerned about . Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE I'm glad you were able to have your questions INFORMATION, STATE: answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/vour concerns were not addressed. I would like to assist you in finding some answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC. STATE: Ms. , I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about . Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT. IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. _____, I will call you back later with additional information.

WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
Ms, you mentioned There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
IF SPOUSE/PARTNER RAISES ANOTHER ISSUE, WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE: While I have you on the telephone, Ms, let me check my files to find some information about Here it is. There is an agency,, that helps to I would like to give you the agency's telephone number so that you can call for more information. Do you have a pen? Here is the telephone number: IF WE HAVE AN IDENTIFIED CONTACT AT THE AGENCY, STATE: When you call, please ask for Mr./Ms
Do you have any other questions or concerns that you would like to discuss today? F NOT, STATE: It has been nice talking with you today, Ms If you have any questions, please write them down so that we can talk about them next month.

SCRIPT FOR AT5 MALE

ANNUAL SCHEDULING CALL

Hello, is this Mr. you? When we talked recently, I let you k Prostate, Lung, Colorectal and Ovarian receive their cancer screenings, I will call person, to help to find answers to your que Medicare, or other health issues. I could e friends, children, and grandchildren.	now that, as part of a research (PLCO) Cancer Screening To you on a monthly basis to ser- uestions about things such as	n project to help rial participants we as a resource Social Security,
Mr, I would like to schedule you	for this year's free cancer scree	ning exam.
First, I would like to ask Have you bee colon or rectum?	n diagnosed with cancer of the	e prostate, lung,
IF NO – CONTINUE. IF YES, DO NOT ORGAN.	SCHEDULE AN EXAM OF	THAT PLCO
Have you had a colonoscopy within the las	t year, or do you plan to have o	ne soon?
IF NO – CONTINUE. IF YES – DO NOT SCHEULE IN BLOOD/X-RAY SLOT.	SCHEDULE THE SIGMOID	OSCOPY AND

This year, your appointment will consist of:

- A blood test
- And the flexible sigmoidoscopy

That is the exam of the lower colon and there is preparation involved, so we will send you a packet containing two Fleet enemas and the instructions. We ask that you eat lightly the night before and the morning of your appointment. It will take approximately an hour and a half to two hours to prepare before you leave your house. The appointment will take approximately an hour and a half to two hours because all of the exams are done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Dewnriver Clinic, on Allen Road, eff of I-75 North.

Which of these is the most convenient for you?

At the (<u>designated clinic</u>) I have <u>day</u>, <u>month</u> and <u>date</u> at <u>time</u> in the morning or <u>time</u> in the afternoon. Which is best for you?

RECORD IN SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID#.

As I mentioned, we will send the letter confirming the day, date, time and location, a map to the location and the Fleet enemas with the instructions.

Is your address (read from the overview)?

After your exams are done, a copy of the results will be sent to both you and your physician, is that still Dr. (read from the overview), (address)?

Mr. _____, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test and the flexible sigmoidoscopy.

IF PARTICIPANT HAS QUESTIONS ABOUT THE PSA TEST, STATE: The PSA test stands for Prostate Specific Antigen Test. PSA is a substance produced only by the prostate, which is one of the male sex glands. A PSA blood test measures the level of PSA in the bloodstream. A high PSA level is a warning sign that cancer may be present, but it is not a sure sign. On the other hand, a low PSA level does not guarantee a cancer-free prostate. The disease may be in an early stage, with PSA not yet showing up in the blood stream.

IF PARTICIPANT HAS QUESTIONS ABOUT THE CHEST X-RAY, STATE: The chest x-ray involves high-energy radiation used in LOW doses to diagnose diseases.

IF PARTICIPANT HAS QUESTIONS ABOUT THE DRE TEST, STATE: A digital rectal exam (DRE) is a simple procedure in which the doctor inserts a lubricated, gloved finger into the rectum and feels the prostate gland for lumps or hardness.

IF PARTICIPANT HAS QUESTIONS ABOUT THE FLEXIBLE SIGMOIDOSCOPY, STATE: During this procedure, a hollow tube is passed through the anus for inspection of the sigmoid colon. The colon is part of the large intestine.

IF PARTICIPANT WANTS TO KNOW WHAT CANCER IS, STATE: Healthy cells grow, divide, and replace themselves in an orderly way, keeping the body in good repair. When this process goes wrong, the result may be cancer. Cancer actually is the general name given to a group of more than 100 diseases, all causing abnormal growth that destroys body tissue. One result of abnormal growth may be the formation of tumors. Tumors are of two types: benign and malignant. Benign tumors are not cancerous. They do not spread to other parts of the body and they are seldom a threat to life. Malignant tumors are cancerous. They can spread and kill nearby healthy tissues and organs. Cancer cells also can break away from a malignant tumor and metastasize — enter the bloodstream and lymphatic system. The lymphatic system is the interconnected system of spaces and vessels between body tissues and organs by which lymph circulates throughout the body. Lymph is a clear, watery, sometimes faintly yellowish fluid derived from body tissues that contains white blood cells and circulates throughout the lymphatic system. Lymph acts to remove bacteria and certain proteins from the tissues, transport fat from the small intestine, and supply mature lymphocytes to the blood.

ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

After the exams are done and the results are in, both you and the physician you designated will receive a copy of the results.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call. Our number is 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

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WRITE DOWN THE THINGS THE PERSON STATES. TRY TO FIND INFORMATION IN OUR FILES TO HELP THE PERSON WHILE YOU HAVE THEM ON THE TELEPHONE. GIVE THE PERSON THE RELEVANT TELEPHONE NUMBER(S). STATE:
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Do you have any other concerns you would like to discuss today? (PROBE AGAIN FOR SPECIFIC CONCERNS. WRITE THEM DOWN AND TRY TO FIND THE TELEPHONE NUMBER OF SOMEONE WHO CAN HELP TO ADDRESS THOSE CONCERNS).
ASK: Mr, did you have any other questions or concerns about something in your own life or the lives of your family or friends?
IF PARTICIPANT CAN'T THINK OF ANY MORE QUESTIONS, STATE: It has been nice talking with you today, Mr If you have any questions, please write them down so that we can talk about them next month. Is your spouse/partner available? IF NOT, STATE: Please let them know that I called and am available to talk with them about any questions or concerns they may have about something in their own lives or the lives of their children, family or friends. I will call again next month.
IF SPOUSE IS AVAILABLE TO TALK, STATE: Hello, is this Ms. ? My name is How are you? When we
talked recently, I let you know that, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I will call your spouse/partner on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, or other health issues. I could even assist you with questions concerning friends, children, and grandchildren. Ms, when we talked last month, you mentioned that you were concerned about Were you able to find the information you were looking for? IF SPOUSE/PARTNER WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

answers. While I have you on the telephone, I will check my files again to see whether I have more information on this topic.

IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms.
______, I will call you back later with additional information. Before we hang up, when we talked last month, you also mentioned that you were concerned about ______. Were you able to find the information you were looking for? IF PARTICIPANT WAS ABLE TO FIND THE INFORMATION, STATE: I'm glad you were able to have your questions answered/your concerns addressed. GO TO NEXT PART OF SCRIPT.

IF SPOUSE/PARTNER WAS NOT ABLE TO FIND THE INFORMATION NEEDED TO ADDRESS THEIR CONCERNS, STATE: I am sorry that your questions were not answered/your concerns were not addressed. IF YOU DON'T HAVE ANY MORE INFORMATION ON THIS TOPIC, STATE: Ms. ______, I will call you back later with additional information.

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WRITE DOWN THE THINGS THE SPOUSE/PARTNER STATES. TRY TO FIND

	you ment I would like to g mation. Do you	rive you the age	ncy's telephone	number so that	you can call for
WE HAV	E AN IDENTIFI for Mr./Ms.	ED CONTACT	AT THE AGE	NCY, STATE:	When you call,
SPECIFIC	ve any other con CONCERNS. NE NUMBER NS).	WRITE TH	EM DOWN	AND TRY T	O FIND THE
THE PERS THE PERS	E/PARTNER R SON STATES. SON WHILE Y THE RELEVAN	TRY TO FIND OU HAVE TI	INFORMATI HEM ON THI	ON IN OUR FI	LES TO HELP
While I ha information l	ve you on the to about would like to go mation. Do you	elephone, Ms Here it is. ive you the agen	There is an a acy's telephone	gency,number so that	, that helps to you can call for
WE HAVE	AN IDENTIFII for Mr./Ms	ED CONTACT	AT THE AGE	NCY, STATE:	When you call,

SCRIPT FOR A T5 MALE

ANNUAL SCHEDULING CALL WHEN THIS IS THE FIRST CALL EVER MADE WITH THE PARTICIPANT

Hello, is this Mr.	? My name is	I'm calling
from the PLCO study at Henry Ford Hospital.	This is your final year of the	free cancer
screening exams and I would like to schedule	your appointment, so that yo	u may take
advantage of them.		•

First, I would like to ask . . . Have you been diagnosed with cancer of the prostate, lung, colon or rectum?

IF NO - CONTINUE. IF YES, DO NOT SCHEDULE AN EXAM OF THAT PLCO ORGAN.

Have you had a colonoscopy within the last year, or do you plan to have one soon?

IF NO – CONTINUE. IF YES – DO NOT SCHEDULE THE SIGMOIDOSCOPY AND SCHEULE IN BLOOD/X-RAY SLOT.

This year, your appointment will consist of:

- A blood test
- And the flexible sigmoidoscopy

That is the exam of the lower colon and there is preparation involved, so we will send you a packet containing two Fleet enemas and the instructions. We ask that you eat lightly the night before and the morning of your appointment. It will take approximately an hour and a half to two hours to prepare before you leave your house. The appointment will take approximately an hour and a half to two hours because all of the exams are done in the one visit.

We do these exams at three locations:

- Our Northwest Clinic, at Outer Drive and the Southfield Freeway between 6- and 7-Mile roads,
- Our Fairlane location in Dearborn near the Fairlane shopping mall, and
- Our Downriver Clinic, on Allen Road, off of I-75 North.

Which of these is the most convenient for you?

At the (<u>designated clinic</u>) I have <u>day</u>, <u>month</u> and <u>date</u> at <u>time</u> in the morning or <u>time</u> in the afternoon. Which is best for you?

RECORD IN SIG SLOT AND ON THE OVERVIEW, PARTICIPANT'S NAME, PHONE # AND PID#.

As I mentioned, we will send the letter confirming the day, date, time and location, a map to the location and the Fleet enemas with the instructions.

Is your address (read from the overview)?

After your exams are done, a copy of the results will be sent to both you and your physician, is that still Dr. (read from the overview), (address)?

Mr. _____, do you have any questions about the PLCO screening you will receive this year? Again, this screening will consist of the PSA test and the flexible sigmoidoscopy.

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ASK THE PARTICIPANT WHETHER HE WOULD LIKE YOU TO WALK HIM THROUGH WHAT WILL HAPPEN AT THE CLINIC, FROM THE TIME HE ENTERS THE DOOR: Mr. _____, would you like me to walk you through what will happen when you arrive at the clinic, from the time you first walk through the door?

IF PARTICIPANT SAYS YES, TELL HIM WHAT WILL HAPPEN.

IF PARTICIPANT SAYS NO, GO TO NEXT PART OF THE SCRIPT.

Thank you, and if there are any questions, either before or after your letter arrives, please don't hesitate to call. Our number is 313-874-6228, and we'll be looking forward to seeing you on (day), (date) at (time) at our (clinic name).

Mr. _____, as part of a research project to help Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Trial participants receive their cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to your questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist you with questions concerning your friends, children, and grandchildren.

Do you have any questions?

Each call will last at least five minutes. You have the right to end the call at any point. You do not have to be a part of this project. You can decide not to take part at the beginning or you can start and then decide to stop. If you do not participate, you will not be a part of this study. The alternative to not taking part is to not participate in this study.

When I call, if it is close to the time of your annual PLCO screening appointment, I will:

- (1) Schedule the date, time, and location of your next screening appointment and the type of screening you will have next;
- (2) Give you directions to the PLCO screening clinic of your choice;
- (3) Answer your questions about the screening procedures, so that you will know what to expect when you arrive for screening;
- (4) Call you to remind you of your scheduled visit;
- (5) Call you if your appointment is not kept, to help with problems you may have had in keeping the appointment; and
- (6) Help you to find transportation if you need it.

I will make every attempt to provide you with the information or resources that you request.

Information about your participation in this project will be kept confidential and only used for research purposes according to applicable state and federal laws. No personal data such as name, address, or social security number will be used to identify you once the project has ended. If you have questions about your rights as a research participant you may contact Ms. Julie Washington in the Research Office at Henry Ford Hospital at (313) 916-2024.

Whatever you decide, you will not receive a penalty or loss of benefits of any sort based upon your decision. Your decision will not affect the medical care you receive from your usual source or your status in the PLCO Cancer Screening Trial. Thank you very much for your time. I look forward to talking with you in the future.

Mr, is your spouse/partner available now? I would like to introduce myself to them, so that when I call, they will know who I am. I can also assist your spouse/partne with questions they may have as well.
Hello, Ms? My name is I am a Henry Ford Health System employee working on the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial. I would like to call your (spouse/partner) on a monthly basis to serve as a resource person, to help to find answers to questions about things such as Social Security, Medicare, health issues or other concerns. I could even assist with questions concerning your friends, children, and grandchildren. I would like to let you know that I would like to serve as a resource person for you as well as Mr When I call, if you have questions, please let me know, and I will do my best to find answers and solutions. Please feel free to ask me questions about anything.

All right. Have a nice day. I look forward to talking with you soon.

SCRIPTS USED WHEN A MESSAGE MUST BE LEFT BECAUSE THE TARGET PERSON IS NOT AVAILABLE

INTRODUCTORY TELEPHONE CALL

Hello, my name is Vernetta Randolph. As part of a research project to help people in the PLCO Study receive their free cancer screenings, I have been assigned to assist you in receiving your screenings. I would like to call you on a monthly basis to serve as a resource person, to help to find answers to questions your or your family may have about things such as Social Security, Medicare, health issues, Head Start or other concerns.

Each call will last at least five minutes.

I will make every attempt to provide you with the information or resources that you and your family request.

Again, my name is Vernetta Randolph. Please call me at 313-874-6228. Thank you. I look forward to hearing from you soon.

FIRST MONTH FOLLOW-UP

Hello, my name is Vernetta Randolph. When I called you recently, I let you know that as part of a research project to help people in the PLCO Study receive their free cancer screenings, I have been assigned to assist you in receiving your screenings. As I stated, I would like to call you on a monthly basis to serve as a resource person, to help to find answers to questions your or your family may have about things such as Social Security, Medicare, health issues, Head Start or other concerns.

Each call will last at least five minutes.

I will make every attempt to provide you with the information or resources that you and your family request.

Again, my name is Vernetta Randolph. Please call me at 313-874-6228. Thank you. I look forward to hearing from you soon.

SECOND MONTH FOLLOW-UP

Hello, my name is Vernetta Randolph. When I called you recently, I let you know that as part of a research project to help people in the PLCO Study receive their free cancer screenings, I have been assigned to assist you in receiving your screenings. As I stated, I would like to call you on a monthly basis to serve as a resource person, to help to find answers to questions your or your family may have about things such as Social Security, Medicare, health issues, Head Start or other concerns.

Each call will last at least five minutes.

I will make every attempt to provide you with the information or resources that you and your family request.

Again, my name is Vernetta Randolph. Please call me at 313-874-6228. Thank you. I look forward to hearing from you soon.

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APPENDIX C

Listing of Community Resources Used in the Retention Study

ADULT DAY CARE

Respite Care

Care For People With Developmental Disabilities

ADULT WELL BEING BUTZEL CENTER

Seniors

Empowerment Zone,

Movies, Picnic, Field Trips

Aarp Materials

Assistance With Cost

Counseling

Health Screenings and Health Lectures

Legal Services

Medicare and Medicaid Assistance

Support Groups

Transportation

Other Activities

Aerobics, Friendship, Games, Needle Craft, Quilting

Business Cards for Seniors

Computer Classes

Food through Focus Hope Food Program

Grandparent Legal Assistance

Prescription Medications

Substance Abuse Prevention Service

AIDS INFORMATION

How AIDS Is Contracted and How It Can Be Prevented

ALZHEIMER'S

Alzheimer's Association of Michigan Detroit Chapter

Educational Program

Helping Hands Respite Care Safe Return Fact Sheet

Kids and Alzheimer's Disease

Library List

Phases of Dementia

Program Summary

- Publication Order Form

Support Group

Things Not To Say to Caregiver

AMERICAN DIABETES ASSOCIATION

American Diabetes Association

Diabetes Information and Action Line

Diabetes Advocacy

Diabetes Diagnosis

Diabetes Facts

Diabetes Resource Catalog

First Things First

Genetics of Diabetes

Healthy Eating

Standards of Care

What is Type I Diabetes?

What is Type II Diabetes?

AMERICAN CANCER SOCIETY

Community Connection

AMERICAN HEART ASSOCIATION PAMPHLETS

Cholesterol and Your Heart

Easy Food Tips For Heart-Health Eating

Exercise

Exercise Diary

Heart Attack and Stroke: Signals and Action

High Blood Pressure

How Can I Monitor My Weight and Blood Pressure?

How Can I Reduce High Blood Pressure?

Managing Your Weight

Now You're Cookin'

Nutrition

Nutrition for Fitness

Nutrition Nibbles

Sodium and Blood Pressure

Spring/Summer 1999 Catalog Professional and layperson training solutions

1-800 numbers

Stroke and Heart Attack

Walking for a Healthy Heart

What Are Stroke and TIA?

What You Should Know About Stroke

What is Your Risk of Brain Attack?

What's Your Risk of Heart Attack?

1999 Heart and Stroke Statistical Update

Why Should I Limit Sodium?

AMERICAN LUNG ASSOCIATION

Facts about Lung Cancer

Facts in Brief about Lung Disease

How to Keep Your Lungs Healthy

The Decision is Yours

The Lung Cancer Resource Center

AREA AGENCY ON THE AGING

Detroit Area Agency on Aging 1999 Directory Eldercare Services

CANCER INFORMATION

American Cancer Society

Barbara Ann Karmanos Cancer Institute

Breast Cancer

Breast Cancer Questions and Answers

Cancer Facts and Figures for African Americans 1998-1999

Cancer Facts for Women

Cancer Facts for Men

Colon and Rectum Cancer

Colorectal Cancer

Guidelines for the Early Detection of Cancer

Healthfinder Questions and Answers

National Institutes of Health

Newsletter: The Health Source

Prostate Cancer: Facts on Prostate Cancer, Testing For Prostate Cancer

Resource Guide

Taking Time Support for People with Cancer and the People Who Care About Them

What You Need To Know about Cancer of the Colon and Rectum

What You Need To Know about Lung Cancer

CHILD CARE

Child Care Centers

COMMUNITY HEALTH AWARENESS

AIDS/HIV

AIDS Fraud Alert

AIDS: What Women Need To Know

Coping with HIV/AIDS

Community Prescription Service

Dental Health Matters

Michigan Jewish AIDS Coalition

Pocket Reterence Guide

What You Should Know About Vidxe (didanosine), DDL and HIV

Case Management

Certified Church Partner

Community Awareness Group

Gay, Lesbian, Bisexual Transgender Community

Breast Cancer Self Examination

COMMUNITY RESOURCE LIST

Advocacy Services Directory

Child Care Coordinating Council of Detroit/Wayne County Directory of Resources for Children and Family

City of Detroit Directory

Detroit Area Hospital Resource List

Detroit Public Library

Michigan Department of Community Health Maternal and Infant Health

Michigan Senior Resource Directory Community Action Agency Index

State of Michigan Family Independence Agency

COMMUNITY SERVICES AND PROJECTS

Bankruptcy Guide

Chiropractic Guide

Christian Credit Counselors

Cosmetic Surgery

Criminal Law

Dental Guide

Detroit Housing Commission Resident Selection Office Application and Placement Process

Education Guide

General Health

General Legal

Mental Health

MetroMatrix Human Services Local Source

Mortgage Guide

News and Entertainment Updates

Pamphlets and Newsletters

Personal Injury

St. Patrick Senior Center

Social Security and Disability

Women's Health

DOMESTIC VIOLENCE

The Michigan Coalition Against Domestic Violence

Wayne County Neighborhood Legal Services Domestic Violence Clinic

EDUCATION

Directory of Health Education Programs - Henry Ford Hospital

Family Road Programs and Educational Classes - Hutzel Hospital

EMERGENCY ASSISTANCE

Detroit Area Numbers

EMPLOYMENT

Census 2000

National Indian Council on the Aging

FAMILY ROAD PROGRAMS

Hutzel Hospital

FAMILY SUPPORT NETWORK OF MICHIGAN

Family Phone Line

Project Find

The Family Place Mental Health Unit

FOOD AND NUTRITION

Detroit Agriculture Network

Focus Hope

Hunger Action Coalition of Michigan

GRIEF AND BEREAVEMENT

Detroit Area Bereavement Centers

Home Health Agencies Henry Ford Hospital

HABITAT FOR HUMANITY

Habitat for Humanity listing

HEALTH CORE

Health Core Henry Ford Hospital

HEALTH EDUCATION CENTER

American Diabetes Society

Breastfeeding

Cancer Information

Depression

Hearing and Aging

Healthy Food

Heart Attacks

Heat Wave information

Menopause

Michigan Fish

Nutrition for Children

Prostate Cancer

Protecting yourself and your baby from sexually transmitted disease

Substance Abuse

Weight Control

What Do I Need to Know about Hepatitis A, B, and C

Work and Family

HELP FOR YOUTH AND FAMILIES

Baseball Sports Coalition

Covenant House

National Runaway Switchboard

Teen Pregnancy

HOME HEALTH CARE

Care Management

Home Health Care Services (State of Michigan)

HOUSING

Senior Housing

State of Michigan Family Independence Agency

IMMUNIZATION FOR CHILDREN

Child Health Network Immunization Project

Grandparent Immunizing for Tots

Starting Early Wayne County

INFORMATION OF MEDICAL CONDITIONS

Alzheimer's Disease

American Stroke Association

Angina Pectoris

Asthma

Brain Attack Stroke

Cholesterol Disorders

Congestive Heart Failure

Crohn's Disease

Depression

Diabetes Mellitus

Epilepsy

FAQ

Glaucoma

Gout

Green Tree

Hypertension

Report by Center for Clinical Effectiveness

Various other diseases

INSURANCE FOR CHILDREN

Detroit Healthy Start Resource Guide

LEGAL ASSISTANCE

Adult Protective Services Program

Designation of Patient Advocate Form

Domestic Violence Shelter Guide

Durable Power of Atto.ney for Health Care Henry Ford Hospital

Jewish Home and Aging Services

MedicAlert

The Legal Brief - the Black Women's Lawyers Association of Michigan

MEDICATION ASSISTANCE Medical Directory Referral List

MEDICAL INSURANCE 1999 Guide Medicare AARP Medical Assistance Detroit Michigan Medical Assistance Program

MICHIGAN RESOURCE CENTER 1999 Publication Catalog 1999 Videos for Loan

RECIPES
Diabetic
Low Fat

SMOKING/QUITTING Facts and Tips for Quitting Involuntary Smoking Smoking and pregnancy

SENIOR CENTER BUTZEL
SEE Butzel Center
Children's Issues

SOCIAL ACTIVITIES
Exercise
Cultural Happenings Detroit
Detroit Public Library
1999 Wayne County Parks Schedule
1999 Summer Activities Guide

SOCIAL SECURITY
Understanding the Benefits

SUBSTANCE ABUSE Boniface Intensive Outpatient Day Treatment Michigan Department of Community Health

TEMPORARY SHELTER "C-O-T-S"

THE SENIOR ALLIANCE AREA AGENCY ON AGING Programs
Senior's Guide http://www.aaa1c.org

TRANSPORTATION

Department of Transportation of Detroit Seniors Services Health Transportation Specialized Transportation

UNITED WAY

Community Services
Guide to Health and Human Services
Resources for Community Problem Solving
Surviving Unemployment